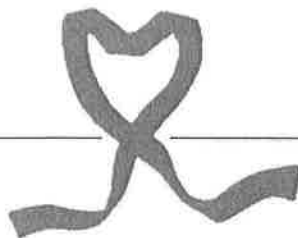


# *The Kimberly Anne Gillary Foundation*

201 West Big Beaver Road,  
Suite 1020  
Troy, MI 48084



Phone: (248) 528.0440  
Fax: (248) 528.3412  
[www.kimberlysgift.org](http://www.kimberlysgift.org)

October 2, 2013

Senate Education Committee Members  
c/o Leta Howard, Committee Clerk  
P.O. Box 30036  
Lansing, MI 48909

Re: HB 4272

Dear Senate Education Committee Members:

My name is Randy Gillary and I am the President of the Kimberly Anne Gillary Foundation ([www.kimberlysgift.org](http://www.kimberlysgift.org)). I am writing in support of the Cardiac Emergency Response Drill Bill, HB 4272 as amended. I would like to respectfully request that the Bill be set for a hearing in the Senate Committee on Education at the earliest possible date. HB 4272 allows any Michigan school to substitute one Cardiac Emergency Response Drill for one of the 8 statutorily mandated fire drills each year. The House Amendment requires those schools with an AED to have at least one such drill. The Amendment is an excellent addition to the Bill.

The Kimberly Anne Gillary Foundation was founded by wife Sue and me after we lost our daughter Kimberly to a sudden cardiac arrest in a water polo game at Groves High School in Birmingham, Michigan on April 1, 2000. Kimmy was 15 years old and was a member of the Troy Athens High School Water Polo Team. She was an excellent athlete and had been swimming since she was 4 years old. The mission of our Foundation is to advocate for cardiac screening and testing of all high school student athletes and the donation of automated external defibrillators (AEDs) to Michigan high schools. Since April of 2000 we have raised more than \$1.2 Million and have donated approximately 650 AEDs to Michigan schools, primarily high schools. We are aware of at least 2 saves of Michigan students and of one grandfather using AEDs donated by our Foundation. Our primary purpose is to prevent other parents from going through what our family went through when we lost our beloved Kimberly.

Some of the reasons why this Bill is important for Michigan are as follows:

1. **We have lost more than 55 students in our Michigan schools since December of 1999 to sudden cardiac arrest and related causes. We appear to have not lost a single student to a school fire in the state of Michigan.** I have attached a list compiled by the

Kimberly Anne Gillary Foundation of 55 students who have died as a result of sudden cardiac arrest and related causes since 2000. This list was compiled primarily from newspaper reports. The Michigan Department of Community Health (MDPH) published a report in June of 2012 entitled *Too Young to Die – An Update on the Impact of Sudden Cardiac Death of the Young in Michigan 1999-2011*. The MDCH Report demonstrates that our numbers are actually significantly understated. There were a total of 246 sudden cardiac deaths among school aged children in the 5 year old to 19 year old age group from 1999 through 2009 based on the investigation done by the MDPH. Please see the table on page 6 of the Report, a copy of which is attached.

I have also attached a copy of a report prepared by the U.S. Department of Homeland Security / FEMA. This report indicates that, "Fires on school property caused an average of approximately 100 injuries. No fatalities were reported during this period." (2003 – 2005) See page one of the Report. I was unable to find any evidence of any loss of life due to a fire in a school in Michigan.

2. **AEDs and Cardiac Emergency Response Drills will save lives.** Based on our survey and our records, we believe that the vast majority of Michigan high schools have at least one AED. Requiring those schools that have at least one AED to perform a Cardiac Emergency Response Drill will help to ensure that staff and students will be adequately prepared to appropriately respond to a sudden cardiac arrest on school property. If a person has a sudden cardiac arrest, there is a window of approximately 10 minutes to revive the person before major brain damage or death will occur. We have been advised by the American Heart Association® that for every minute wasted the chances of major brain damage or death increases by 10%. A Cardiac Emergency Response Drill is essentially a practice run to make sure that staff and students can timely and effectively respond to a sudden cardiac arrest. Time is of the essence and practice helps to ensure that when a sudden cardiac arrest does occur, the staff and students know exactly what to do. This is a matter of life and death and there will likely be a lot of anxiety and emotion. We cannot afford for our staff and students to be trying to figure out what to do next. The Drills will help to prevent that.


You have noticed that I believe students, in addition to staff members, should be involved in the Drills. Please check out the story in the following link which describes how several students saved one of their class mates. It is more likely that there will be more students than staff near a person at school who has a sudden cardiac arrest.

Wasserman, Scott (2012, Nov. 9). "Teammates Save Swimmer Whose Heart Stopped in Pool". Retrieved from <http://www.myfoxtwincities.com/story/19800795/teammates-save-swimmer-whose-heart-stopped-in-pool>

- 3. The primary objective that we as parents, educators and legislators have is to first make sure that our sons and daughters survive high school.** My wife and I as well as many other mothers and fathers, know full well the trauma of losing a child due to a sudden cardiac arrest at school. This Bill will help to reduce the chances that other parents will suffer as we have done.

Please feel free to contact me if you have any questions or if you would like to discuss this with me in more detail.

Thanks very much for your consideration.

Sincerely,  
  
Randall J. Gillary – Kim's DAD

RJG:ek  
Enc.





## *The Kimberly Anne Gillary Foundation*

201 W. Big Beaver Road  
Suite 1020  
Troy, MI 48084

Phone (248) 528-0440  
Fax (248) 528-3412  
[www.kimberlysgift.org](http://www.kimberlysgift.org)

### **Known Instances of Sudden Cardiac Arrest (SCA) Resulting in Death of Michigan Students:**

<u>Date</u>	<u>Name</u>	<u>School Group</u>	<u>Age</u>	<u>City</u>	<u>Cause</u>	<u>Sport</u>
December 1999	Craig Stille		20	Holland	HCM	
January 2000	Seaborn Harvey	High School	16	Detroit		Basketball
January 2000	Mark Bolger	High School	16	Plymouth-Salem		Basketball
March 2000	Matthew Smith	High School	14	Clawson	Heart Damage	
April 2000	Kimberly Gillary	High School	15	Troy	HCM	Water Polo
August 2000	Jeremy Tarlea	High School	16	Saline	Heat Stroke	
December 2000	Sarah Ruthenburg	Middle School	13	Traverse City	HCM	
April 2001	Nick Rose	High School	17	Harper Woods		Tennis
May 2001	John Munley	College	22	East Lansing	HCM	Jogging
May 2001	Jonathan Nugent	College	20	Alma		Softball
October 2001	Stuart Zurvalec	Middle School	12	Bay City		Baseball
January 2002	Nicholas Blass	Middle School	13	Waterford		Gym Class
February 2002	Mary Elkins	High School	15	Rochester		
April 2002	Deon Simpson	High School	14	Detroit		Basketball
May 2002	Derek Smith	College	19	Grand Rapids	Heart Defect	Basketball
September 2002	Eric Simpson	High School	15	Detroit		Football
September 2002	Matt Sklom	College	18	Big Rapids		Football
April 2003	Lela Johnson	High School	15	Grand Haven		Basketball
November 2003	Thomas Winfrey	High School	15	Detroit	HCM	Basketball

January 2004	Alban Berishaj	Middle School	11	Waterford	Basketball
February 2004	Nicholas Lindsay			Detroit	Football
April 2004	Alecia Holst	College	21	Mt. Pleasant	CMU Concert
June 2004	Katy Rader	Middle School	12	Bad Axe	Basketball
					Heart Defect
January 2005	Karl Hollis	Middle School	13	Detroit	Basketball
May 2005	Marissa Towler	Middle School	10	Whitmore Lake	Track
November 2005	Mackenzie Watts	High School	15	Howell	Swimming
March 2006	Kayla Stanford	Middle School	12	Ypsilanti	Track
May 2006	Jamarl Fordham	High School	16	Birmingham	Basketball
July 2006	John Bowden	High School	16	Farmington	Soccer
					HCM
May 2007	Taylor Grainger	Middle School	14	Mattawan	Congenital Heart Condition
November 2007	DeAndre Brown	High School	17	Detroit	Basketball
February 2008	DeShawn Hodgkinson	High School	17	Charlevoix	Track
October 2008	Scott Loundmon, III		19	Southfield	Basketball
November 2008	O'Shea Martin	Middle School	13	Detroit	Sitting/ Class
December 2008	Jessica Clemente	High School	16	Marine City	
January 2009	Michael Jefferson	High School	15	Ann Arbor	Gym Class
February 2009	Zachary Johnston	High School	17	Auburn Hills	Wrestling
March 2009	Thomas R. Hill, III	College	25	Ypsilanti (EMU)	Basketball
June 2009	Dorian Dawkins	High School	14	Saginaw	Basketball
July 2009	Unnamed	Juvenile Detention	17	Highland Park	Basketball
September 2009	Jackie Marolf	College	18	East Lansing (MSU)	In dorm room
November 2009	Dustin Minix	High School	18	Jackson	On the phone
					Pre-existing Condition
January 2010	Nathaniel Hernandez	High School	14	Fennville	Home/ after Wrestling
August 2010	Dillon Menard	College	19	Sault Ste. Marie (LSSU)	In dorm room
September 2010	Name not released	Elementary School	10	Grand Rapids	After school program
October 2010	Ariael Lombard	High School		Detroit	During school
January 2011	Thomas Smith	High School	17	Flushing	At home
March 2011	Wes Leonard	High School	16	Fennville	Basketball
March 2011	Peter Catcho	High School	17	West Bloomfield	At home
February 2012	Sharon Arwood	Middle School	13	Fraser	Running in Gym Class
September 2012	Bryson Salem	College	18	Walled Lake	Basketball @ Lifetime

December 2012	David Widzinski	High School	16	Novi	Heart Arrhythmia	At home
January 2013	Toron Murphy, Jr.	High School	17	Detroit		Just arrived at school
February 2013	Anna Flory	College	19	Hudsonville		At apartment at MSU
March 2013	Mario Campbell	High School	16	Ferndale		Track Practice



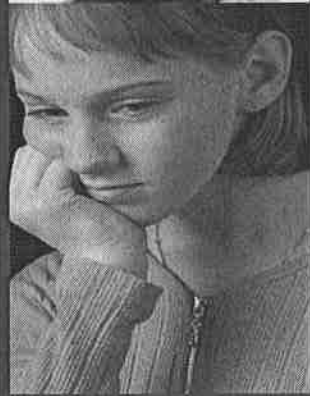




Rick Snyder, Governor  
Olga Dazzo, Director

# *Too Young to Die*

**An Update on the  
Impact of Sudden Cardiac Death  
of the Young in Michigan  
1999-2011**



**“...no important health problem will be solved by clinical care alone, or research alone, or by public health alone- but rather by all public and private sectors working together...”**

**- JS Marks. Managed Care 2005**



**For further information, please contact:  
Michigan Department of Community Health**

**Genomics and Genetic Disorders Section**

Division of Genomics, Perinatal Health and Chronic Disease Epidemiology

201 Townsend St.

PO Box 30195

Lansing, MI 48909

1-866-852-1247

[www.michigan.gov/scdy](http://www.michigan.gov/scdy)

## **Table of Contents**

<b>Chapter 1:</b> <b>PUBLIC HEALTH SIGNIFICANCE</b>	<b>2</b>
<b>Chapter 2:</b> <b>OVERVIEW OF THE MICHIGAN SCDY SURVEILLANCE AND MORTALITY REVIEW SYSTEM</b>	<b>3</b>
-Expert Mortality Review	
<b>Chapter 3:</b> <b>EPIDEMIOLOGY OF SCDY IN MICHIGAN</b>	<b>5</b>
-Michigan Mortality Data	
-Michigan BRFSS and Family History of SCDY	
<b>Chapter 4:</b> <b>STRATEGIES AND OPPORTUNITIES FOR PREVENTION</b>	<b>12</b>
-Provider Education on SCDY Risk Assessment and Public Awareness of Risk Factors	
-Pre-participation Sports Screening	
-Public Awareness of Cardiac Symptoms and AED/CPR Training	
-Emergency Response Protocols	
-Medical Examiner Protocols	
<b>Chapter 5:</b> <b>MICHIGAN'S PROGRESS IN SCDY PREVENTION</b>	<b>17</b>
<b>TABLES</b>	
1. SCDs of Michigan residents, 1999-2009	<b>6</b>
2. 10 most frequent causes	<b>7</b>
3. Family history of SCDY	<b>10</b>
4. Family history of SCDY & Health-related factors	<b>11</b>
5. Action Steps	<b>19</b>
<b>FIGURES</b>	
1. Age-adjusted mortality rates by county	<b>5</b>
2. SCDYs by age and sex	<b>7</b>
3. Top 10 causes by race	<b>8</b>
4. Top 10 causes by sex	<b>9</b>
5. SCDYs by year	<b>9</b>
<b>APPENDICES</b>	
A. Key Steps	
B. Expert Review Process	
C. ICD-10 Codes	
D. Mortality Rates by County	
E. Common Causes	
F. History Questions	
G. References	

# **Impact of Sudden Cardiac Death of the Young in Michigan 1999-2011**

## **Introduction**

The Michigan Department of Community Health (MDCH) is pleased to present this updated report detailing the impact of sudden cardiac death (SCD) in Michigan young people under age 40—an issue of grave public health concern. SCD is especially devastating when it occurs in children or young adults in the prime of life who were previously thought to be in good health. These deaths are a tremendous loss not only for families, but for entire communities, as evidenced by the often high profile media attention.

MDCH first identified sudden cardiac death of the young (SCDY) as a potentially preventable condition in 2004. A number of surveillance projects to identify SCDY trends occurred from 2005-2011. Analysis of mortality data for the years 1999-2009 has revealed:

- As many as 329 out-of-hospital SCDY occurring each year
- The statewide age-adjusted mortality rate as 5.5 per 100,000 with 9 counties having higher rates than the state average
- Significant disparities with more than two-thirds of the deaths occurring in males, and one-third in blacks
- Dilated cardiomyopathy as the most commonly reported underlying cause for SCDY at 1-29 years of age
- Atherosclerotic cardiovascular disease as the most commonly reported underlying cause for SCDY at 30-39 years of age.

In addition, a telephone survey of 2,856 Michigan adults conducted as part of the Behavioral Risk Factor Surveillance System (BRFSS) in 2007 revealed that about 6.3% have a family history of early SCD in one or more relatives, with a higher rate among black respondents (11.2%).

Based on expert review of selected Michigan SCDY cases from 2006-2008, 21 strategies to prevent SCDY were identified and in 2008, approximately 60 stakeholders from diverse organizations gathered to recommend next steps. From 2009-2011, significant progress has occurred with many of the strategies implemented by MDCH and partners.

The following chapters of this report highlight actual excerpts from reviewed cases and completed actions to date. Investigation of these deaths has led to identification of individual, family, public and provider needs and motivated policy makers to initiate changes to prevent future SCDY. The effectiveness of the human story to convey the burden of SCDY in the state is an instrumental tool to motivate partners and initiate prevention activities, and helps to put a personal face to each of the 3,134 SCDY that have occurred in Michigan. Our hope is that all individuals in Michigan who have experienced a SCDY in their family will know that they are not forgotten and that there are many who care.

We are thankful for the numerous partners who have contributed to this work. The partnership of all concerned individuals and organizations is needed to further increase early identification, treatment and intervention—because victims of SCD are too young to die—and every life lost is one too many.



## **Chapter 1**

# **Public Health Impact and Significance**

Reducing early mortality due to heart disease is an important priority for public health. Heart disease is the second leading cause of premature death as measured by years of potential life lost for males and females of most races, except for black males in whom it is the leading cause of early mortality. Overall, heart disease at any age is the leading cause of mortality in Michigan and has been for over a hundred years.<sup>1,2</sup>

The estimated number of SCDY occurring in Michigan varies depending on the definition. For this report, SCDY is defined as a death that occurred:

- Between 1-39 years of age;
- In the emergency room, en route to the hospital, out of the hospital, or dead on arrival to the emergency room;
- In Michigan to a Michigan resident; and was
- Cardiac-related, due to a congenital cardiac malformation, or had an ill-defined/unexplained underlying cause.

Using this definition, SCDY is estimated to claim the lives of as many as 329 Michigan children and young adults each year. Of these deaths, approximately 10% are in children and teens under age 20. About 40% occur in individuals between 20 and 34, while nearly half occur between 35 and 39 years of age. Moreover, survey data reveal that about 6.3% of all Michigan residents report having at least one biological family member who died suddenly and unexpectedly at a young age.<sup>3</sup>

Although SCDY is a relatively rare occurrence when compared to SCD in older adults, it has a devastating impact not only on the family but on the larger community as well. When they occur, the tragic nature of these deaths frequently attracts media attention. Questions are often asked, especially--

### ***"Could this death have been prevented?"***

Concern about the public health impact of SCDY prompted the MDCH Genomics Program and the Cardiovascular Health, Nutrition and Physical Activity Section to identify sudden cardiac death of the young (under age 40) as a potentially preventable condition, and our work in Michigan to address this public health issue began in 2003.

SCDY has critical implications for the victim's family, especially if the death was related to an inherited condition. Advances in understanding the hereditary causes of SCD have led to the realization that individuals with a family history of SCD have an increased risk of suffering a sudden death themselves.<sup>4</sup> New findings have emerged about the benefits of identification, treatment and follow-up to reduce the risk of early cardiac death. Many single genes associated with disorders that may lead to SCDY have been identified.<sup>5</sup> Furthermore, in the past decade, hundreds of new loci associated with polygenic cardiovascular risk factors for SCDY have been discovered. However, the translation of these new gene discoveries to prediction of risk and prevention of disease requires additional research.

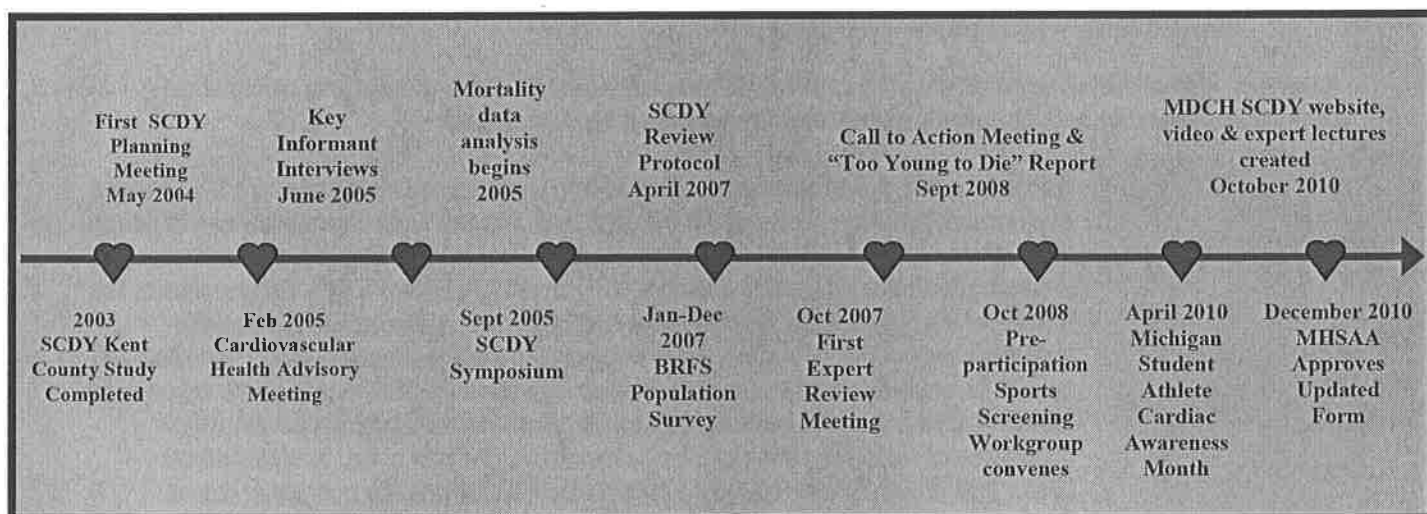
## Chapter 2

# Overview of the Michigan SCDY Surveillance and Mortality Review System

To address the public health impact of SCDY, MDCH first established a retrospective system for monitoring SCDY based on incoming death certificates filed with the State Registrar. Statewide population-based surveillance and epidemiological review of SCDY is a novel endeavor. To our knowledge, no other state public health agency has attempted to systematically assess and address this cause of early mortality. Several events led to the concept of a state-based SCDY surveillance and mortality review project. As shown in the timeline below, a study by Dr. Michael Lehman and colleagues in 2003 first brought attention to the problem of SCDY in Michigan.<sup>6</sup> The researchers examined records on unexpected deaths to people between 1 and 39 years of age who had received an autopsy in Kent County. The investigators found SCDY occurred mainly in males, 50% of the deaths were due to coronary artery disease, and family history documentation was lacking in medical examiner records.

As shown in the timeline below and in **Appendix A**, a series of steps were taken between 2004 and 2008 to identify key stakeholders, examine the need for surveillance, and ultimately establish a mortality review system with short-term goals to:

- ♥ Develop and refine a process to collect and review demographic and mortality data regarding SCDY in Michigan residents.
- ♥ Conduct epidemiological assessments of the burden of SCDY in Michigan.



## Expert Mortality Review

In 2006, MDCH Genomics Program collaborated with Michigan State University (MSU), Division of Environmental and Occupational Medicine to develop a rapid case investigation and review process as part of a SCDY surveillance system for Michigan. The goals of this pilot mortality review system were to:

- ♥ Implement and refine a process to collect and review medical data and other circumstantial information regarding SCDY cases;
- ♥ Use the expert review process to identify recommendations as a first step toward evidence-based medical system changes and public health prevention efforts that will reduce the occurrence of SCD in Michigan; and
- ♥ Identify unmet needs for family-based interventions including education, support, medical/genetic resources and referrals for relatives who may be at increased risk of SCD themselves.

To our knowledge, this is the first statewide mortality review system that included notification to next-of-kin about possible genetic risks and the need to screen immediate relatives. The mortality review process and outcomes were detailed in a recently published article.<sup>7</sup>

The mortality review process included collecting information from death certificates, medical facilities, medical examiners, emergency responders, and family members. The process of rapidly identifying and reviewing cases is detailed in **Appendix B**. Deaths occurring to a Michigan resident aged 1-39 years between January 2006 and April 2008 were identified by MDCH Division of Vital Records and Health Statistics on a quarterly basis. Cases were then selected for in-depth review based on the decedent's age, geographic location, and underlying cause of death as coded on the death certificate and likelihood of a true "sudden death." For selected cases, MSU conducted next-of-kin interviews and collected pertinent records including autopsy results and emergency response reports. A summary of each case was prepared with all identifiable information removed.

Case summaries were reviewed by a panel of experts representing the multiple disciplines of emergency medicine, pediatric and adult cardiology, medical genetics, cardiac pharmacology, public health, pathology, primary care, sports medicine, nursing, and health insurance. For each case, the panel was asked to:

- ♥ Confirm the cause of death listed on the death certificate or suggest an alternative diagnosis;
- ♥ Describe all significant factors that may have contributed to the death, including health system or community issues such as access to an automated external defibrillator (AED) in the location where the death occurred;
- ♥ Determine the likelihood that additional family members could be at risk and attempt to determine whether appropriate medical interventions for family members were identified or had been recommended; and
- ♥ Suggest recommendations related to the patient, provider, and system levels that could have prevented the reviewed death or future deaths in the family.

If deemed appropriate by the expert panel, the next-of-kin were notified by MDCH to provide information about potential heritable risks and the importance of screening immediate family members.



Medical records, including autopsy reports, were obtained and reviewed on 23 SCDY cases that occurred between 2006 and 2008 in Michigan. The two most common causes of death in these cases were attributed to cardiomyopathy (7 cases) and fatal arrhythmia (6 cases). A possible heritable cause was attributed to 17 of the 23 cases (73.9%). Sixteen next-of-kin interviews were conducted; most of these next-of-kin were not aware of the possible heritable cause of SCDY and were also not aware of the importance of family screening. All next-of-kin received introductory and follow-up letters from MDCH regarding the expert case review. If appropriate, the next-of-kin follow-up letters included information about the importance of screening immediate family members. The next of kin, family members and/or their providers were encouraged to contact MDCH with any questions. Some families and their providers did contact MDCH for additional information and specifics about

appropriate screening for family members. **Follow-up evaluations of immediate family members, even in the absence of a known SCDY cause of death, can lead to potential prevention of sudden death in the surviving family members.**

Based on review of these SCDY cases, the expert panel identified 21 prevention measures grouped into five themes (also see Table 5):

- ♥ Provider education and public awareness of SCDY risk factors
- ♥ Enhanced pre-participation sports screening, physical examination and follow-up
- ♥ Public awareness of cardiac symptoms and training in the use of cardiopulmonary resuscitation (CPR) and AED for coaches and the general public
- ♥ Creation and dissemination of emergency response protocols
- ♥ Creation and dissemination of medical examiner protocols for possible SCDY cases

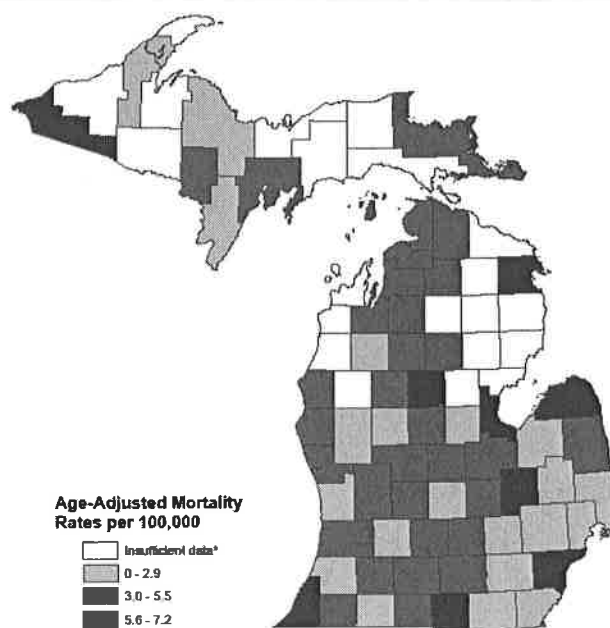
## Chapter 3

# Epidemiology of SCDY in Michigan

**Who** is affected by SCDY?  
**Where** do most deaths occur?  
**Why** do these deaths happen?

To understand the burden of sudden death in Michigan young people, mortality data spanning the time period from 1999-2009 were examined for residents between 1 and 39 years of age whose underlying cause of death was reported on the death certificate using specific codes based on the International Classification of Diseases-Version 10 (ICD-10) system (**Appendix C**). All inpatient hospital deaths were excluded. A retrospective methodology was used to examine death certificates similar to previously published studies.<sup>8</sup> Cases were assigned to one of three groups according to eligible codes that included **cardiac** (I00-I51 except I12-13 and I26-28), **congenital cardiac malformation** (Q20-Q24 and Q87.4) or **ill-defined** (R96-R99) etiologies. Analysis of death certificate data alone does not provide potential explanations for reasons for death—for instance, the impact of environmental or behavioral factors such as smoking, drug or alcohol use, obesity or level of physical activity. Although there is ambiguity regarding some of the codes used to report underlying causes of death, the MDCH Division for Vital Records and Health Statistics classifies reported deaths to Michigan residents in accord with national coding requirements. This retrospective code-based method may result in an overestimation of true SCD cases. Further assessments of SCDY using *multiple* sources of case ascertainment (i.e., death certificates, emergency medical response, medical examiners, hospitals), as previously described in our expert mortality process, enhance the accuracy of the data.

**Figure 1**  
**Age-Adjusted Mortality Rates of SCDY among Michigan Residents, Ages 1-39 by County of Residence, 1999-2009**



\*Counties with fewer than five sudden cardiac deaths from 1999-2009  
Michigan's age-adjusted mortality rate is 5.5 per 100,000  
Source: MDCH Vital Statistics  
Age-adjusted to the 2000 U.S. standard population



From 1999-2009, there were 3,134 deaths that met Michigan's case definition for SCDY based on death certificates filed with the State Registrar. The statewide age-adjusted mortality rate for children and young adults aged 1-39 was 5.5 per 100,000 residents. There were significant differences between counties of residence, as depicted in **Figure 1**. Nine counties had mortality rates for residents that were higher than the statewide rate, including Alpena (7.2), Claire (7.1) and Genesee (6.7) counties. Wayne County had the largest number of deaths (1,166), followed by Oakland (251), Macomb (203), Genesee (164), and Kent (146) counties. The numbers and rates for all Michigan counties are included in **Appendix D**.

Data were also analyzed by sex, race, place of death, autopsy status, and cause of death (**Table 1**). Significant disparities were observed for sex and race, with more than two-thirds of the deaths occurring in males, and one-third in blacks. **The greatest numbers of SCDY were reported in adults ages 35-39 years.** Nearly 47% of individuals died in the emergency room or were dead on arrival, whereas 43% died at home. An autopsy was performed in more than three-quarters of the cases (79%).

Overall, the rate for males was 7.6 per 100,000 and for females, 3.4 per 100,000. The rate for blacks (12.2 per 100,000) was significantly higher than the rate for whites (4.3 per 100,000). **The single highest age-adjusted mortality rate was for black males at 16.5 per 100,000** which is nearly two-and-a-half times the rate for white males (6.1 per 100,000). The rate for black females was 8.3 per 100,000, more than **triple** the rate for white females (2.4 per 100,000) [Data not shown].

The lowest mortality rate was for the 1-9 year old group at 1.0, followed by the 10-19 year old group at 1.2 and the 20-29 year old group at 4.1 per 100,000. There was a dramatic increase between those in their 20s and those in their 30s, with the highest mortality rate for the 30-39 year old age grouping at 14.5 per 100,000.

**The significantly increased mortality rate in the 30-39 year old group requires further investigation into possible modifiable risk factors associated with these deaths.**



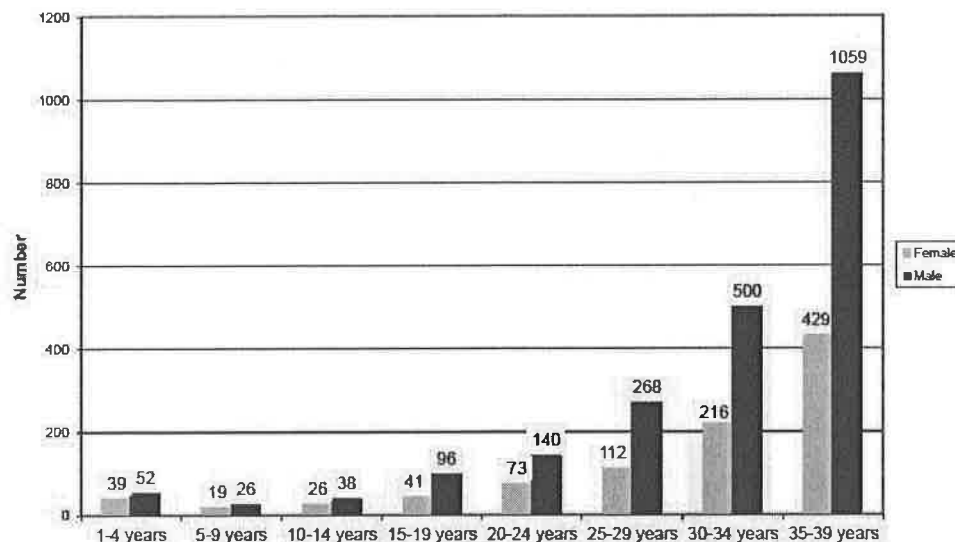
<b>Table 1</b> <b>Sudden cardiac deaths* of Michigan residents</b> <b>aged 1 - 39 years, 1999 - 2009</b>		
	Number	Percent
<b>Total</b>	<b>3,134</b>	
<b>Sex</b>		
Male	2,179	69.5
Female	955	30.5
<b>Race</b>		
White	1,961	62.6
Black	1,089	34.7
Other	84	2.7
<b>Age</b>		
1-4 years	91	2.9
5-9 years	45	1.4
10-14 years	64	2.0
15-19 years	137	4.4
20-24 years	213	6.8
25-29 years	380	12.1
30-34 years	716	22.8
35-39 years	1,488	47.5
<b>Place of death</b>		
Home	1,339	42.7
Nursing home, extended care	28	0.9
Hospital: emergency room / outpatient	1,462	46.6
Ambulance	34	1.1
Other / unknown	271	8.6
<b>Autopsy</b>		
Yes	2,474	78.9
No	658	21.0
Unknown	2	0.1

\* Includes decedents who died out of the hospital, or in an emergency department, or were dead on arrival to an emergency department, and had one of the identified ICD-10 codes reported as the underlying cause of death on the death certificate



Significant disparities were also observed for age and sex (Figure 2). For all age groups analyzed, males were more commonly affected with SCDY than females. The largest disparity between sexes was observed in the 35-39 year old age group, with males comprising approximately 70% of cases.

**Figure 2**  
Number of SCDY in Michigan residents aged 1-39 years, by age and sex, 1999-2009



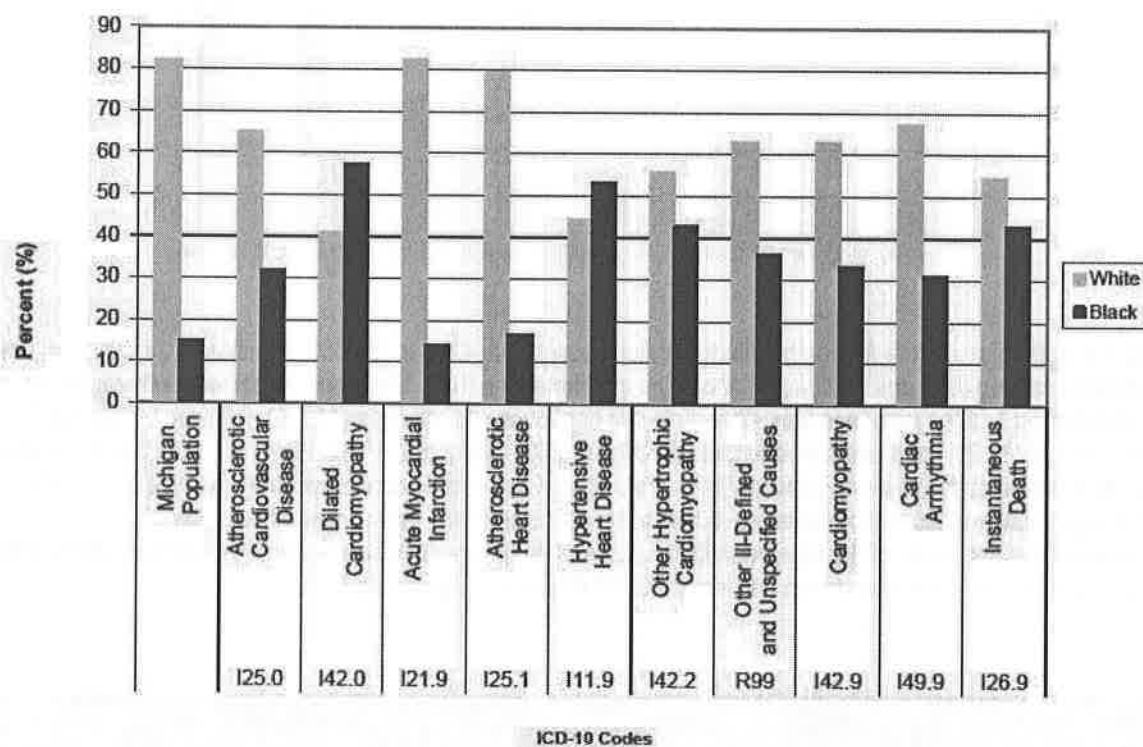
The overall age-adjusted rate for deaths due to cardiac causes was 4.8 per 100,000, significantly higher than rates for ill-defined causes (0.4) and for congenital cardiac malformations (0.3). The single most frequently reported cause of death between 1-39 years of age was atherosclerotic cardiovascular disease (14.8%), followed by dilated cardiomyopathy (14.2%) and acute myocardial infarction (10.6%), as noted in Table 2. In contrast, the single most frequently reported cause of death between 1-29 years of age was dilated cardiomyopathy (41.1%; n=122) [Data not shown]. Significant genetic components are known to be associated with early onset atherosclerosis, cardiomyopathies and many of the other identified causes of death which include anatomical and arrhythmogenic cardiac disorders. For a list of common causes of SCDY, please see Appendix E.

**Table 2**  
Ten most frequent underlying causes of death of Michigan SCD victims, 1-39 years, 1999-2009 (n=3,134)

ICD 10 Code	Cause of death	Number	Percent
I25.0	Atherosclerotic cardiovascular disease	464	14.8
I42.0	Dilated cardiomyopathy	444	14.2
I21.9	Acute myocardial infarction	331	10.6
I25.1	Atherosclerotic heart disease	303	9.7
I11.9	Hypertensive heart disease without heart failure	221	7.1
I42.2	Other hypertrophic cardiomyopathy	180	5.7
R99	Other ill-defined and unspecified causes of mortality	124	4.0
I42.9	Cardiomyopathy	121	3.9
I49.9	Cardiac arrhythmia	109	3.5
I26.9	Instantaneous death	86	2.7

The relative frequency of different SCDY etiologies also varies by sex, race and age. For the top ten causes of SCDY, there were notable differences by race, with **blacks disproportionately represented among deaths relating to any cause except acute myocardial infarction and atherosclerotic heart disease**. In the 1-39 year old age group, the most commonly reported underlying cause in blacks was dilated cardiomyopathy (n=255) while in whites it was atherosclerotic cardiovascular disease (n=301) (Figure 3). In the 1-29 year old age group, the most commonly reported cause of death was dilated cardiomyopathy for blacks and whites. Among deaths due to dilated cardiomyopathy in the 1-29 year old age group, approximately 60% (n=72) were among blacks [data not shown]. Among deaths in the 1-39 year old age group, dilated cardiomyopathy and hypertensive heart disease were notably higher among blacks compared to whites and the deaths in blacks comprised more than half of all deaths due to those two etiologies (Figure 3).

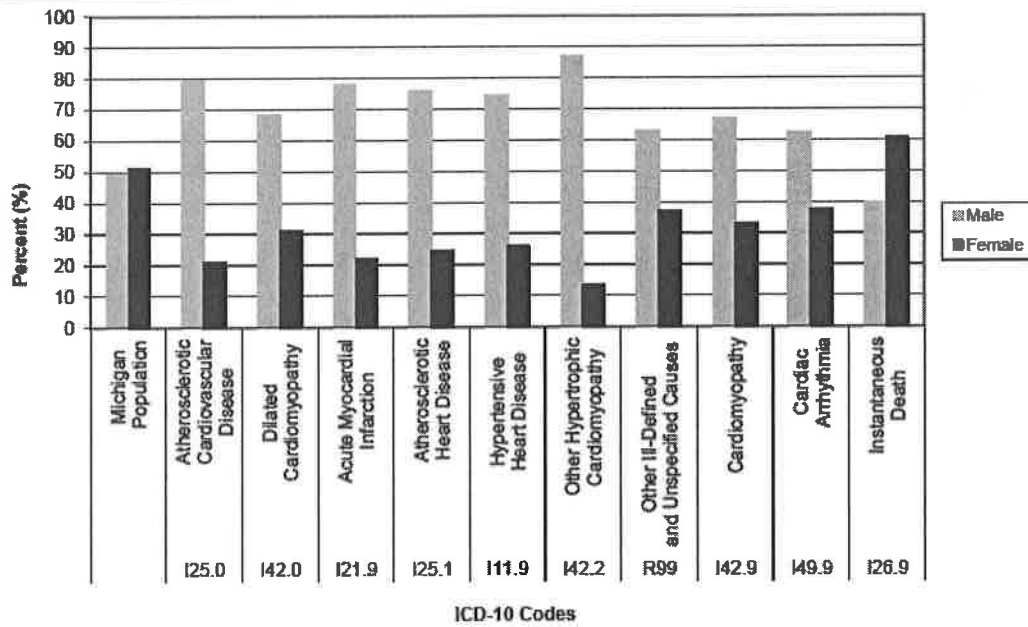
**Figure 3**  
Top ten causes of SCDY by race, Michigan residents aged 1-39 years, 1999-2009



There were also notable differences between males and females, with males more likely than females to die of SCDY for all age groups and most of the ten top SCDY causes. However, the one exception was for SCDY between 1-39 years of age, in which females were more likely to die of instantaneous death. The greatest difference between males and females was in the "other hypertrophic cardiomyopathy" category where females comprised just less than 14%, while males represented 86% of all deaths (Figure 4).

**Figure 4**

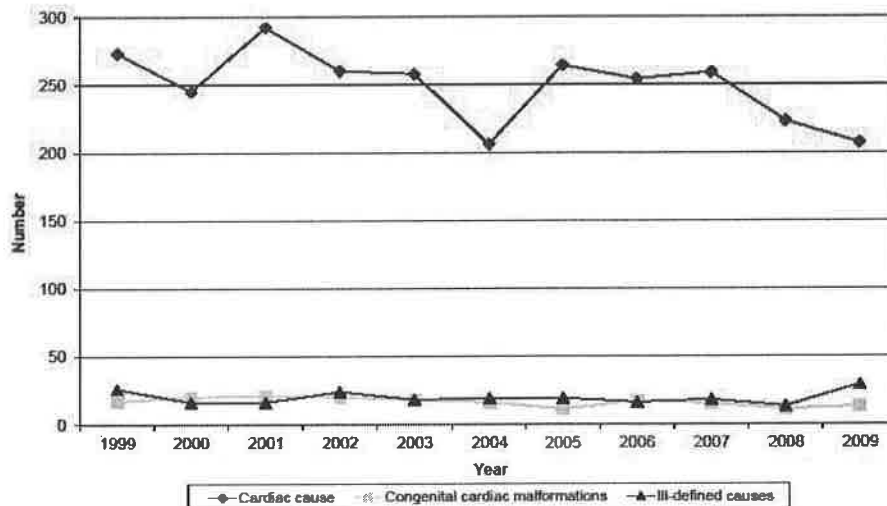
Top ten causes of SCDY by sex, Michigan residents aged 1-39 years, 1999-2009



There was little year to year fluctuation in the number of SCDY cases due to congenital and ill-defined causes. A slight decrease in cardiac cases was observed in 2008 and 2009 (Figure 5), but it is unclear whether this is a new trend or normal variation. MDCH will continue to gather data in coming years.

**Figure 5**

Number of SCDYs in Michigan residents aged 1-39 years, by year and underlying cause of death, 1999-2009





### Michigan BRFS and Family History of SCDY

Although age, sex, and race/ethnicity are risk factors for SCDY, the greatest risk factor is family history.<sup>9</sup> In fact, as much as 40% of families with a victim of SCDY have been identified as having a heritable disease. Collection of family history of SCDY is a vital first step to identify, screen, and manage individuals at greatest risk for SCDY.

Despite increased risks for family members, it appears that family history of SCDY is rarely documented in the clinical setting.<sup>10</sup> There is a paucity of reports in the medical literature on the psychosocial, emotional or clinical follow-up of family members of SCDY victims. Therefore, in 2007, using the Michigan BRFS ([www.michigan.gov/brfs](http://www.michigan.gov/brfs)), we surveyed 2,856 Michigan adults about their family history of SCDY.

Overall, the proportion of adults in Michigan reporting a family history of early sudden cardiac or unexplained death was 6.3% (Table 3). Of adults reporting a family history, 35.5% had an immediate relative (parent, sibling, or child) and 26.2% had multiple family members that had SCDY. The most commonly reported family member who had SCDY was a sibling. This is significant since individuals with multiple affected family members and/or an affected first degree relative are known to have the greatest risk based on their family history.

**Table 3**  
**Family History of Sudden Cardiac Death of the Young<sup>a</sup>**  
*2007 Michigan Behavioral Risk Factor Survey*

	%	95% Confidence Interval
<b>Total</b>	<b>6.3</b>	<b>(5.2 - 7.7)</b>
<b>Age</b>		
18 – 24	3.8	(1.6 - 8.7)
25 – 34	8.6	(4.9 - 14.6)
35 – 44	4.2	(2.4 - 7.1)
45 – 54	7.7	(5.4 - 10.9)
55 – 64	5.9	(4.1 - 8.5)
65 – 74	8.5	(5.4 - 13.3)
75 +	5.4	(3.5 - 8.2)
<b>Gender</b>		
Male	5.4	(3.9 - 7.4)
Female	7.7	(6.1 - 9.6)
<b>Race/Ethnicity</b>		
White non-Hispanic	5.4	(4.3 - 6.8)
Black non-Hispanic	11.2	(7.7 - 16.0)
Other non-Hispanic	9.4	(3.8 - 21.3)
Hispanic	-- <sup>b</sup>	
<b>Education</b>		
Less than high school	10.8	(5.8 - 19.3)
High school graduate	8.8	(6.6 - 11.7)
Some college	4.7	(3.3 - 6.8)
College graduate	4.4	(2.8 - 6.8)
<b>Household Income</b>		
< \$20,000	7.8	(5.1 - 11.7)
\$20,000 - \$34,999	8.4	(5.9 - 11.8)
\$35,000 - \$49,999	8.8	(5.5 - 13.8)
\$50,000 - \$74,999	4.1	(2.1 - 7.9)
\$75,000 +	3.2	(1.9 - 5.2)

<sup>a</sup> Among all respondents (n = 2,856), the proportion who reported having at least one biological family member that had a sudden cardiac death, or sudden unexplained death, between the ages of 1 and 39.

**Note:** Interviewers were instructed not to include spouses of the respondent, infants less than one year of age, as well as drug-related deaths, traumatic deaths (such as car crashes), suicides, homicides, or individuals who had a long illness.

<sup>b</sup> The denominator in this subgroup is less than 50.

**Table 4**  
**Prevalence of health-related characteristics among Michigan adults by**  
**family history of SCDY**  
**2007 Michigan Behavioral Risk Factor Survey**

Health-Related Characteristic	Has Family History of SCDY	
	Yes % (95% CI)	No % (95% CI)
No health insurance	17.8 (11.0-27.5)	10.6 (9.0-12.5)
On Medicaid insurance	23.1 (15.4-33.1)	10.6 (9.0-12.4)
No personal doctor	13.0 (7.9-20.5)	15.0 (12.9-17.4)
No routine checkup in past year	29.3 (20.1-40.5)	31.3 (28.7-34.0)
No blood cholesterol test in past 5 years	27.4 (17.9-39.6)	20.1 (17.6-23.0)
<b>Health Status</b>		
Fair to poor general health	16.1 (11.1-22.7)	14.3 (12.6-16.2)
Rarely-never receive needed emotional support	12.3 (7.1-20.4)	6.2 (5.1-7.6)
Has a disability	26.4 (19.6-34.6)	21.8 (19.8-23.9)
Obese (BMI $\geq$ 30)	34.0 (25.0-44.4)	27.6 (25.2-30.2)
<b>Chronic Conditions</b>		
Ever diagnosed with high blood pressure	39.5 (30.8-49.1)	27.9 (25.8-30.2)
Ever diagnosed with high cholesterol (among tested)	42.4 (33.0-52.4)	40.8 (38.1-43.5)
Ever diagnosed with diabetes	13.1 (8.9-19.1)	8.6 (7.5-9.9)
Ever diagnosed with cardiovascular disease	10.0 (6.2-15.8)	9.5 (8.3-10.9)
<b>Behaviors</b>		
Current smoking	32.2 (23.3-42.6)	20.1 (17.9-22.6)
No leisure-time physical activity	20.2 (13.3-29.5)	19.3 (17.2-21.5)
Inadequate physical activity	48.3 (38.2-58.5)	47.3 (44.5-50.0)
Inadequate fruit and vegetable consumption	82.4 (75.6-87.6)	78.1 (75.7-80.2)



Consistent with the health disparities found among SCDY victims (Table 1), there are considerable differences in the proportion of respondents with a family history of SCDY by racial/ethnic background (Table 3). Blacks had the highest reported prevalence of SCDY family history at 11.2%, more than double the prevalence of white non-Hispanic adults, 5.4%. Adults with a household income of less than \$50,000 also reported family history of SCDY more frequently than those with a household income of \$50,000 or more. Adults with a high school degree or less education more often reported a family history of SCDY than those with some college education. Among those with a family history of SCDY, there was also a significantly higher proportion who reported having Medicaid insurance compared to those without a family history (23.1% vs. 10.6%).

Furthermore, those with a family history of SCDY also had a significantly higher proportion of people who had ever been diagnosed with high blood pressure (39.5% vs. 27.9%) and a higher proportion who were current smokers compared to those without such a family history (32.2% vs. 20.1%) (Table 4). These data highlight the need to collect family history of SCDY on all individuals, identify high-risk individuals and initiate public health and clinical interventions to reduce the burden of SCDY.



## Chapter 4

# Strategies and Opportunities for Prevention

Certain causes of SCD in younger adults and children are more likely to have genetic determinants than similar conditions in older persons. These include inherited arrhythmias, hypertrophic cardiomyopathy, undetected congenital heart defects and early coronary artery disease/atherosclerotic disease. Over the last decade, there has been significant progress in identifying inherited disorders that increase the chance of SCDY.<sup>11,12,13</sup> There have also been major strides in uncovering new genes, mechanisms and syndromes that have significantly advanced the diagnosis and treatment of genetic SCDY disorders.<sup>14</sup> These advances can enhance presymptomatic diagnosis and help establish definitive molecular diagnosis for symptomatic patients.<sup>15</sup> Furthermore, recent discoveries about genotype-phenotype correlations can now assist providers in predicting risk factors and selecting treatment for patients with inherited arrhythmic disorders.<sup>16</sup> **Despite the major advances in cardiovascular genetics, a careful review of personal and family health history remains the current standard for assessing SCDY risk.**<sup>17</sup> Throughout this chapter, each section includes blue boxes quoting excerpts from our expert mortality review which highlight the need for action to prevent SCDY in Michigan.

### Provider Education on SCDY Risk Assessment

Collection of personal and family history is an effective and simple method for providers to screen and identify individuals at risk for SCDY. From 2005-2007, MDCH worked with a major Michigan health plan to conduct a review of 668 charts from Michigan primary care providers (i.e. pediatric, family medicine, internal medicine). Disturbingly, less than 1% of these charts indicated that the provider had inquired and documented the presence or absence of a family history of SCDY.<sup>18</sup>

It is critical for providers to be aware of personal and family risk factors for SCDY. Cardiovascular risk assessment should be administered at routine intervals starting in early childhood. There are specific personal and family history questions<sup>19</sup> that can indicate a potential risk for SCDY including:

- ⇒ Unexplained syncope/fainting particularly during exercise, emotion or startle
- ⇒ Chest pain or discomfort during exercise
- ⇒ Excessive, unexpected and unexplained shortness of breath or fatigue associated with exercise
- ⇒ Past detection of heart murmur, high cholesterol, myocarditis, or increased systemic blood pressure
- ⇒ Family history of premature death in close relatives younger than 50 years old, including unexplained accidents, drowning, SIDS
- ⇒ Family history of unexplained syncope
- ⇒ Family history of congenital deafness
- ⇒ Family history of individuals with pacemakers or automatic implantable cardioverter-defibrillators (ICDs)
- ⇒ Specific knowledge of the occurrence of certain familial conditions associated with SCDY [see Appendix F]

After their son died in his 20s, the parents learned that he had been complaining of chest pain and shortness of breath for a couple weeks but did not feel he needed medical attention.

An example of a risk assessment form for use in the clinical setting was published by Campbell and Berger in 2006.<sup>20</sup> For those identified with a significant personal or family history of SCD and/or related heart conditions, referral to a cardiologist and/or clinical geneticist who specializes in conditions known to be associated with SCD should be considered.

### Pre-participation Sports Screening

One opportunity for primary prevention of SCDY that has received substantial national and international attention is to identify high risk athletes through pre-participation screening. Importantly, SCD is the leading cause of death in young athletes.<sup>21</sup> Hypertrophic cardiomyopathy (HCM) is the single most common cause of death among U.S. athletes, occurring most commonly in those playing football and basketball. Male athletes are more likely to die suddenly than female athletes (male:female ratio for SCDY is up to 9:1). Sudden Cardiac Death of the Young is also disproportionately more likely to occur in African American athletes.<sup>22</sup> Identification of athletes at high risk for SCDY





is critical in order to prevent adverse events. However, since athletes with unsuspected cardiovascular disease can appear healthy, it can be difficult for providers to detect 'silent' cardiovascular abnormalities than can lead to sudden death without a careful history and examination.

### ***International Guidelines for ECG Pre-Participation Sports Screening***

Guidelines for screening athletes differ widely on an international, national and state basis.<sup>23,24,25,26,27,28,29,30</sup> Many professional sports leagues, the International Olympic

Committee and some countries routinely incorporate the use of ECGs with the physical and health assessment for early detection of cardiovascular abnormalities in athletes. A national screening program in Italy led to a 10-fold reduction in the incidence of SCDY in competitive athletes (with a 7% false-positive rate) over a 25 year period, while a study conducted in Israel did not find the rate of SCDY to be affected by mandatory mass ECG screening over a 12 year period.<sup>31,32</sup>

### ***Mass Universal ECG Pre-Participation Sports Screening Not Currently Recommended in the United States***

There has been considerable debate in the United States about the appropriate strategies, effectiveness and logistics of various pre-participation screening methods.<sup>33,34</sup> Evidence-based guidelines for pre-participation screening of non-professional athletes currently do not exist, and national research on the best method of conducting pre-participation screening for athletes has led to inconsistent conclusions.<sup>35,36</sup> A recent study of 400 healthy children (5-19 years of age) in Philadelphia who received history and physical examination, ECG and echocardiograms detected 5.8% with previously undiagnosed cardiac abnormalities.<sup>37</sup> The authors concluded that ECG was three times more likely than history and physical examination alone to identify true abnormalities.

The American Heart Association (AHA) supports pre-participation cardiovascular screening for student-athletes in organized competitive sports as "justifiable, necessary, and compelling on the basis of ethical, legal and medical grounds." However, the AHA Council on Nutrition, Physical Activity and Metabolism did not believe it to be... "prudent or practical to recommend the routine use of tests such as 12-lead ECG or echocardiography in the context of mass, universal screening" it concedes that "...such a complex initiative would have benefit in terms of detecting greater numbers of athletes with important heart diseases." The Council also did not "...arbitrarily oppose volunteer-based athlete screening programs with noninvasive testing performed selectively on a smaller scale in local communities if well designed and prudently implemented."<sup>38</sup>

Studies in support of ECG screening are evolving rapidly with more rigorous ECG criteria leading to lower total positive rate and reduced levels of false positives.<sup>39</sup> If SCDY is found to be more common than previously suspected and the accuracy of ECG screening continues to increase, mass ECG screening may become more feasible in the United States. In 2010, a group from Stanford University using computer simulation concluded that screening young athletes with 12-lead ECG plus cardiovascular focused history and physical examination may be cost effective.<sup>40</sup> In 2011, a National Heart, Lung and Blood Institute (NHLBI) working group published support for development of a research agenda to further clarify the national incidence of SCDY and determine the best approach to reduce SCDY.<sup>41</sup> The research would evaluate if screening with ECG effectively reduces SCDY and adds overall healthcare value.

### ***Current Consensus on Pre-participation Sports Screening in the United States***

Despite differing opinions among cardiology experts on the value and feasibility of including additional elements such as routine ECG screening, there is general agreement nationally on the basic elements of cardiovascular screening. The AHA and American College of Sports Medicine recommend that an athlete pre-participation evaluation include detailed family history and physical examination. The recommended 12-point screening protocol for young competitive athletes includes:

As reported during his pre-participation sports screening, he had been experiencing vague symptoms for the past several months. His heart skipped beats, he was dizzy when getting up from a chair, his legs hurt and he was tired all the time. The teen thought the symptoms meant he was out of shape so he would practice harder. A few days before his death, he told his mother "I'm going to die... my heart's going to stop."

1) A personal history to assess palpitations, exertional chest pain/discomfort, unexplained syncope/near syncope (fainting), exertional unexplained dyspnea/fatigue, and elevated systemic blood pressure and heart murmur;

2) A family history to assess premature death, disability from heart disease in a close relative younger than 50 years old, and known cardiovascular genetic conditions; and

3) A physical exam to assess heart murmur, femoral pulses, physical stigmata of Marfan syndrome and brachial artery blood pressure.

If there is a significant finding in the history or physical, a 12-lead ECG, echocardiogram, exercise testing and/or cardiovascular consultation should be considered. Parental verification of any responses provided by a youth is essential for secondary education students.<sup>42,43</sup>

The mother voiced concern over the fact that the sports physical form was not seen, filled out, or signed by her. After his death, she found a letter her son had received clearing him to play sports.

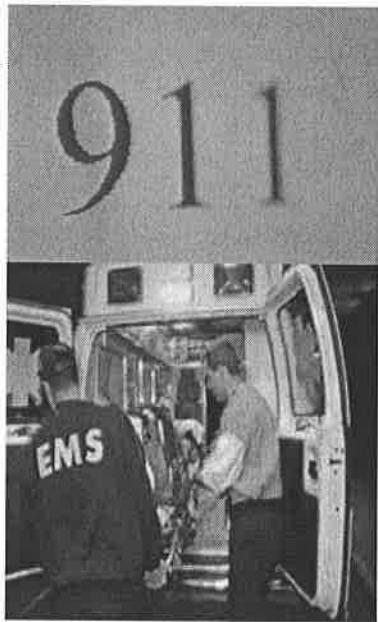
In 2010, the American Academy of Family Physicians, American Academy of Pediatrics, American College of Sports Medicine, American Medical Society for Sports Medicine, American Orthopaedic Society for Sports Medicine, and American Osteopathic Academy of Sports Medicine published the fourth edition of a pre-participation physical evaluation monograph that includes a recommended pre-participation history and physical form, (**Appendix F**).<sup>44</sup> The physical exam includes a focus on detecting the heart murmur of left ventricular outflow tract obstruction and physical findings suggestive of Marfan syndrome. **Patients suspected or identified to be at risk for SCDY by the history or exam should be referred to a cardiovascular specialist for further evaluation.** In addition, providers should be aware that guidelines for athletes with known genetic conditions, such as hypertrophic cardiomyopathy (HCM), and known coronary artery disease have been published.<sup>45,46,47</sup>

### Public Awareness of Cardiac Symptoms and AED/CPR Training

Sudden cardiac arrest (SCA) most often results from a sudden, unexpected heart arrhythmia such as ventricular fibrillation during which the heart's electrical impulses become chaotic and ineffective. Blood flow to the brain is lost and death usually follows unless a normal heart rhythm is quickly restored. Defibrillation with a device such as an AED provides an electrical shock to re-establish the heart's normal rhythm and is the only known treatment for ventricular fibrillation.<sup>48</sup>

Availability of an AED provides the opportunity for secondary prevention of early deaths. However, symptoms of possible cardiac arrest must first be recognized by bystanders, and an AED must be accessible by trained users with a target goal of three to five minutes from time of collapse to first shock. Currently the chance of surviving SCA is less than five percent. The AHA has identified a "Chain of Survival" that increases the likelihood of survival. The sequence of four steps includes early access (recognizing an emergency exists and calling 911), early CPR, early defibrillation and early advanced care.<sup>49,50</sup>

*An AED was not available during the practice and the boy's coach did not have training on how to use one.*



According to the AHA, early CPR and defibrillation within the first three to five minutes after collapse, plus early advanced care can result in greater than 50% long-term survival for witnessed ventricular fibrillation events.<sup>51</sup>

### Emergency Response Protocols

EMS response time in most communities in the United States has been reported to range from 12-15 minutes.<sup>52</sup> The time delay is related to many factors, including the time to activate EMS by telephone, arrival of EMS at the site, parking of the rescue vehicle, and initiation of first defibrillation shock. The AHA advocates for equipping all EMS first-response vehicles and ambulances with an AED or other defibrillation device. It also supports "Public Access to Defibrillation" (PAD), which means making AEDs available in targeted public and/or private places where large numbers of people gather or where people who are at high risk for cardiac arrest live—venues such as sports



arenas, gated communities, office complexes, shopping malls, etc. When AEDs are placed in the community, they need to be part of a defibrillation program that includes notification of the local EMS office, oversight by a licensed medical authority to ensure quality control, and training in both CPR and use of the defibrillator for persons responsible for using the AED.<sup>53</sup>

The deceased's sports team was not affiliated with the school district or the city's recreation program. The coach told the family there was an AED in the building where the deceased had collapsed but it was locked in an office and not available.

The National Athletic Trainers' Association has convened a task force to ensure an efficient response to SCA.<sup>54,55</sup> The task force states that it is critical for schools to be prepared for cardiac emergencies. They recommend that structured emergency action plans should be developed through discussion with local EMS, school safety officials, first responders and school administrators. The task force further notes that the emergency plan should be practiced annually; the first responders should be trained and certified in CPR and defibrillation; the collapse-to-EMS call time and CPR initiation should be less than one minute;

and the access to early defibrillation must have a target time of less than three to five minutes from time of collapse. They also state that SCA should be suspected for any collapsed and unresponsive athlete. Finally, the task force developed uniform recommendations for management of SCA in athletes, similar to the "chain of survival" recommendations- early activation of EMS, early CPR, early defibrillation, and rapid transition to advanced cardiac life support.<sup>56,57</sup> These guidelines are comparable to statements that have been published by AHA taskforces and other organizations on this issue.<sup>58</sup>

While the effectiveness of widespread AED availability in the secondary prevention of SCDY is unknown, a number of individuals and families who have survived SCA or lost a loved one to SCDY have started foundations to advocate for placement of AEDs in schools and other public areas.<sup>59,60,61</sup>

### Medical Examiner Protocols

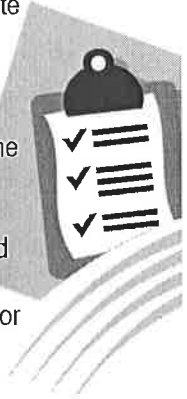
*Sudden Cardiac Death* describes an unexpected, non-violent, non-traumatic death occurring out of hospital, or in the emergency room, or being dead on arrival. Sudden cardiac death is usually defined as death from a cardiac cause occurring within one hour from onset of symptoms; however, the time frame for onset of symptoms varies in definitions from 1 to 24 hours.<sup>62,63</sup> Some definitions further specify whether the death was witnessed or unwitnessed and the amount of time since the victim was last seen without acute symptoms in his/her usual state of health.

*Sudden Cardiac Death of the Young* has been variably defined as occurring in people under the age of 25, 30, 35, or 40 years.<sup>64</sup> Most often the term is used for deaths to individuals between the ages of 1 and 39, which is the age range used for identifying cases in Michigan's SCDY surveillance program. Sudden Cardiac Death of the Young generally occurs in the emergency room or at home with the underlying cause of death reported as cardiac disease (ICD-10 codes: I00-I51). However, the selection of a specific ICD-10 code as the underlying cause of death is often ambiguous; for instance, the rationale for selecting "I26.9 instantaneous death" over the myriad of other available codes for SCDY remains unclear. **One important limitation of the SCDY surveillance project identified by the expert panel is an inconsistency in coding the cause of death (ICD codes) on death certificates. Therefore, there is an urgent need to standardize reporting by medical examiners and others in order to improve data accuracy, completeness and comparability across the state and nationally.** The advent of electronic medical records and data reporting systems may present an opportunity for achieving more consistency.

### Need for Autopsy and Implications for Family Members

When a young person dies suddenly, it is imperative to investigate the underlying cause in order to identify possible risks for other family members. Routine autopsy can detect some structural conditions that predispose to SCDY but ideally the autopsy examination should be performed by a pathologist with cardiac expertise and appropriate samples be taken for histological and DNA analysis.<sup>65</sup> To our knowledge, there is no published evidence-based protocol or universal procedure that medical examiners follow when investigating SCDY in the United States. However, there are advocacy groups that recommend a mandatory autopsy for all cases of SCDY, and have issued recommendations for the postmortem process.<sup>66</sup> Other countries have also established SCDY uniform protocols for medical examiners, including recent guidelines by the Association of European Cardiovascular Pathology.<sup>67</sup>

It is critical to review autopsy information in light of possible genetic implications for surviving family members, and consider DNA testing or banking as part of the post-mortem work-up. Both health care providers and families need to



be aware that the presence of SCDY in a biological relative may increase the risk for many other family members due to numerous underlying genetic causes. **It is the potential impact on the entire family that makes a thorough investigation, including autopsy and careful medical consideration of genetic causes, vital in every case of SCDY.** In the case of familial hypertrophic cardiomyopathy (HCM), a structural cause of SCD often identified on autopsy, there is a one in two chance that first degree relatives (parent, sibling, or child) also inherited the gene for this condition. Clinical recommendations for screening high risk individuals (based on history of an affected family member) include clinical assessment with electrocardiogram (ECG) and echocardiogram at regular intervals starting in childhood. Genetic testing for HCM is also commercially available, and allows for early detection prior to the expression of typical clinical findings.

In contrast to "single gene" disorders such as HCM, the etiology of coronary artery disease is typically more complex, based on both genetic and behavioral/environmental causes (multifactorial). Certain lifestyle choices, such as smoking, high-fat diet, and lack of physical activity, are known risk factors. However, when a young person dies of coronary artery disease, there is likely a strong underlying genetic predisposition. Family members should, therefore, be carefully screened for risk factors related to early coronary artery disease so they can modify other preventable risk factors and monitor for development of coronary artery disease.

### ***Molecular Autopsy***

About 30% of young sudden deaths have negative autopsies.<sup>68</sup> Because electrical and other conditions will not be detected, it is not unusual for a routine autopsy to conclude that the cause of death was indeterminate. In such cases, heritable conditions such as cardiac ion channel disorders, are suspect and genetic analysis could help to elucidate the cause of death and prevent future deaths in families at risk.<sup>69,70</sup> Post-mortem DNA testing is commonly referred to as a "molecular autopsy". Studies have found that molecular autopsy leads to a specific diagnosis with a known deleterious mutation in about 30-40% of cases.<sup>71,72</sup> Detecting a mutation has also been shown in some studies to be more likely when there is more than one SCDY in a family<sup>73</sup> and in SCDY cases with a syncope history.<sup>74</sup> When a routine autopsy is inconclusive or negative, continued investigation through cardiology and genetic evaluation of first or second degree relatives or a molecular autopsy may help to determine the underlying cause of the SCDY.<sup>75</sup> Laboratories conducting DNA testing for various causes of SCDY can be found at: [www.genetests.org](http://www.genetests.org). DNA testing can be quite costly; however, funding assistance may be available in some situations.

A white female in her 20s was found unresponsive and lying in bed. After a full autopsy, examination of histologic tissue sections and full toxicology, the cause and manner of death were undetermined. There was no documentation that DNA testing or banking was considered.

Since current genetic technology can detect less than half of SCDY cases with known deleterious mutations, DNA testing for families is most informative when it includes testing the affected individual's DNA first; otherwise, 'negative' DNA test results on family members will be uninformative.<sup>76</sup> An appropriate assessment of family members is highly dependent on determining the cause of the SCDY. Once the specific cause of death has been determined, the best approach is to use a stepwise assessment or cascade screening through the family to identify key individuals most likely to benefit from screening.<sup>77</sup> Another approach to consider is combining molecular autopsy with family cardiac screening.<sup>78</sup> Newer technologies are emerging that will make DNA testing even more effective.<sup>79</sup>

### ***DNA Banking***

DNA banking is another important option to consider when SCDY occurs. DNA banking is offered through a number of clinical laboratories that can be found at: [www.genetests.org](http://www.genetests.org). DNA banking by a clinical laboratory is typically not covered by insurance. However, some medical examiners in Michigan routinely store a dried blood spot from autopsies. Also, if DNA banking or autopsy were not considered at the time of death, another approach to obtaining DNA from a deceased individual is through stored newborn screening dried blood spots. In fact, a study in New Zealand of 21 cases of SCDY utilized stored dried blood spots to conduct molecular autopsies up to 13 years after death.<sup>80</sup> In Michigan, there exists an important resource of archived newborn screening dried blood spots that are stored by the MDCH. With permission from a parent, guardian or next-of-kin, these archived blood spots could be used for molecular testing to further investigate causes of death in those born in Michigan since 1984.<sup>81,82,83</sup>

## Chapter 5

# Michigan's Progress in Preventing SCDY, 2008-2011

In September 2008, a "Call to Action" meeting to address SCDY was attended by approximately 60 individuals representing a diverse group of organizations that included professional medical societies, hospitals, health plans, industry, faith-based groups, academia, and foundations. The attendees were asked to identify the most appropriate and feasible immediate next steps to prevent SCDY in Michigan. Since 2008, over 50 additional individuals have joined our efforts to prevent SCDY. Table 5 provides an overview and status report on key action steps identified as a result of the original mortality review process, with progress in specific areas highlighted below.

"I thought we were forgotten....  
I thought no one cared..."

— Mother of 18 year old victim, upon being asked for a next-of-kin interview

### Provider Education on SCDY Risk Assessment and Public Awareness Of Risk Factors

From 2009-2011, a multitude of educational resources were created—including a website, video, and expert presentations—to increase provider and public awareness of personal and family history risk factors. In addition, several press releases and newspaper articles drew public attention to the issue of SCDY. Many partners held educational events to increase public and provider awareness and prevention of SCDY; and there have been numerous presentations at national and state conferences about Michigan's efforts to prevent SCDY. For example, in September 2011, educational initiatives were implemented by three key partners. The University of Michigan held an event to increase provider knowledge regarding SCDY in Ann Arbor (view at: <http://www.uofmhealth.org/protectinghearts>). Spectrum Health conducted public service announcements including local radio and television interviews and held an educational event in Grand Rapids to increase public awareness about SCDY risk factors. Genesee County Health Department and Community Based Organization Partners (CBOP) held an event in Flint to increase public awareness about SCDY risk factors. It is estimated that over 10,000 individuals were reached regarding SCDY with these three activities alone. Information regarding educational resources and upcoming events is available at [www.michigan.gov/scdy](http://www.michigan.gov/scdy).

### Pre-participation Sports Screening

The Michigan High School Athletic Association (MHSAA) is a private, not-for-profit corporation with over 1,500 middle and high school members that agree to abide by MHSAA policies.<sup>84</sup> These schools have approximately 315,000 high school and middle school students who participate in school athletics per year. The MHSAA Handbook includes a regulation that 'no student shall be eligible to represent a high school for whom there is not on file in the offices of the superintendent or principal or athletic director of that school, statements for the current school year certifying that the student has passed a physical examination'.<sup>85</sup> From 2008-2010, MDCH convened a workgroup to make formal recommendations to MHSAA regarding updates to align its pre-participation sports screening history and exam forms with national recommendations.

In 2010, the workgroup's recommended form was provided to MHSAA with letters of support from over 20 Michigan professional organizations and advocacy groups. MHSAA subsequently approved this recommendation and updated its medical history form template.<sup>86,87</sup> The history and exam portions of the form can now be accessed at: [www.michigan.gov/scdy](http://www.michigan.gov/scdy) or [www.MHSAA.com](http://www.MHSAA.com). The history form, including 12 questions to assess SCDY risk factors, must be completed by an adult parent or guardian unless the student-athlete is 18 years of age or older. If the personal, family history and/or exam reveal significant findings, a referral to cardiology for consideration of appropriate evaluations, such as an ECG and/or echocardiogram, are suggested prior to clearance of the athlete.

**MHSAA is now one of the first state athletic organizations in the United States to be aligned with current national recommendations.** In 2011, MHSAA created an awareness campaign to disseminate health messages regarding heart, head, heat and medical history for their member organizations.<sup>88</sup> With this important policy change, it is hoped that public awareness about SCDY risk factors and provider practice regarding collection and documentation of SCDY risk factors in Michigan will increase.

## Public Awareness of Cardiac Symptoms and AED/CPR Training

Public awareness of SCDY and the need to recognize cardiac symptoms appears to be increasing in Michigan. For instance, April 2010 and April 2011 were declared Michigan Student Athlete Awareness Month by the Michigan House of Representatives and Senate as a statewide effort to increase awareness and prevention of sudden cardiac events in students.<sup>89</sup>

In 2011, the MHSAA conducted a survey that revealed 93% of schools who responded (n=346) have AEDs; however, only 73% indicated that an AED is readily available at all athletic venues.<sup>90</sup>

Furthermore, 67% of respondents reported that there is no requirement by their school for coaches to be certified to provide CPR/AED or first aid assistance. Several Michigan foundations, created by families whose child died as a result of SCDY at a school athletic event, have continued to donate AEDs to schools. Additionally, the first Michigan chapter of the Sudden Cardiac Arrest Association (SCAA) was formed in 2011 by Beaumont Hospital. SCAA is an organization that works to increase awareness of SCA and public access to defibrillation. Additional information on public awareness is available at [www.michigan.gov/scdy](http://www.michigan.gov/scdy)

There is currently no state law that mandates placement of AEDs in schools; however in 2011 and 2012, bills were introduced in the state legislature that would require schools to have AEDs in place, emergency response plans, and required AED training for personnel. Michigan already has a Good Samaritan Act for CPR and AED that protects individuals who in good faith voluntarily render CPR and/or AED to another individual from civil action damages.<sup>91</sup> There is currently no federal or state funding to implement CPR and/or AED training and placement in schools. MDCH and Michigan pediatric cardiologists are therefore investigating the feasibility of becoming an affiliate of Project ADAM to provide CPR and AED trainings and resources to schools at a voluntary community level.

## Medical Examiner Protocols

In 2011, MDCH worked with University of Michigan cardiologists and the Washtenaw County Medical Examiner to create a standardized checklist for SCDY cases for integration into a new electronic death certificate reporting system. MDCH has also been working with the University of Michigan and interested Michigan pathologists to further investigate causes of SCDY through autopsy reports. Activities regarding medical examiner protocols will be a primary focus and further explored in coming years.



## Future Steps for Prevention of SCDY

In 2010, MDCH and partners were pleased to learn that the NHLBI convened a Working Group to develop a national research agenda and to identify resources to evaluate whether screening for SCDY would effectively reduce SCD and add health care value. The Working Group was unanimous in stating the importance of preventing SCD, but decided that more research is required to determine the best national approach to achieve this goal. Specific areas to be addressed were strikingly similar to our Michigan work, including prospectively defining the incidence and epidemiology of SCDY; the development and evaluation of protocols for screening populations for SCDY; and, protocols for management of individuals with a known condition at risk for SCDY.<sup>91,92</sup> The NHLBI research agenda includes development of a SCDY registry, with resources leveraged through existing infrastructure of the National Center for Child Death Review using state-based child death review teams to assist with this activity.<sup>91</sup> The National Center for Child Death Review is administered by the Michigan Public Health Institute, and has recently become a new partner involved with our efforts. For instance, MDCH recently authored a SCDY factsheet to be utilized by state-based child death review teams which can be found at: <http://www.childdeathreview.org/causesNOO.htm>. MDCH will continue to work with the National Center for Child Death Review, NHLBI and our partners to determine the best approach to prevention of SCDY. For further updates or to become involved in our efforts, please visit [www.michigan.gov/scdy](http://www.michigan.gov/scdy)



**Table 5**  
**Overview of Action Steps from Expert Panel Review & Current Progress to Prevent SCDY**

Themes	Action Steps Identified by Expert Panel	2009-2011 Progress
<b>Provider Education and Public Awareness of SCDY Risk Factors</b>	Increase public awareness and provider assessment of SCDY risk factors & family history, through various means and multiple different health system contact points	Events for providers and public in 2009-2011
	Identify clinical screening protocols for those with family history of SCDY	Completed in 2010
	Consider developing continuing medical education regarding SCDY risk factors, assessment, referral and treatment for health providers	Provider education events in 2009-2011
	Emphasize the need for case management for young adults with chronic disorders (such as diabetes, hypertension, high cholesterol, heart defects, & obesity)	Ongoing
	Identify options for obtaining medications for uninsured and underinsured individuals at risk for SCDY, and disseminate to providers	No progress
	Increase awareness and access to appropriate medical and/or genetic services for individuals with a family history of SCDY	Ongoing
<b>Pre-Participation Sports Screening/ Physical and Follow-up</b>	Make recommendations to MHSAA to revise sports participation form based on mortality case findings and national guidelines	Completed in 2010
	Identify and disseminate clinical guidelines for evaluation and management of students with known conditions at risk for SCDY	Expert presentations in 2010-2011
	Identify and/or disseminate recommendations to coaches about symptoms and/or conditions that may place athletes at higher risk	Events held for coaches in 2011
<b>Public Awareness of Cardiac Symptoms &amp; CPR/AED Training</b>	Explore existing state mandates for CPR and AED training	Ongoing
	Increase appropriate availability of AEDs and trained users	Ongoing
	Increase awareness of cardiac symptoms and appropriate actions	Ongoing
	Increase public and community knowledge of CPR	Ongoing
<b>Emergency Response Protocols</b>	Explore appropriateness of response time and initiation of immediate defibrillation for SCA cases; provide feedback to EMTs	Ongoing
	Investigate availability of AEDs for all responders	Ongoing
	Make formal clinical recommendations regarding appropriate use of medications in SCDY situations to appropriate EMS organizations	No progress
<b>Medical Examiner Protocols</b>	Suggest consideration of DNA banking for SCDY cases; explore expense and insurance reimbursement options for DNA banking	Ongoing
	Increase awareness of familial risks among medical examiners	Ongoing
	Develop mechanism to ensure autopsy results and recommended follow-up are conveyed to families and primary providers	Ongoing
	Develop suggested protocols for autopsy of SCDY cases	Ongoing
	Consider pilot to independently assess pacemakers function after SCDY	No progress



## Appendix A

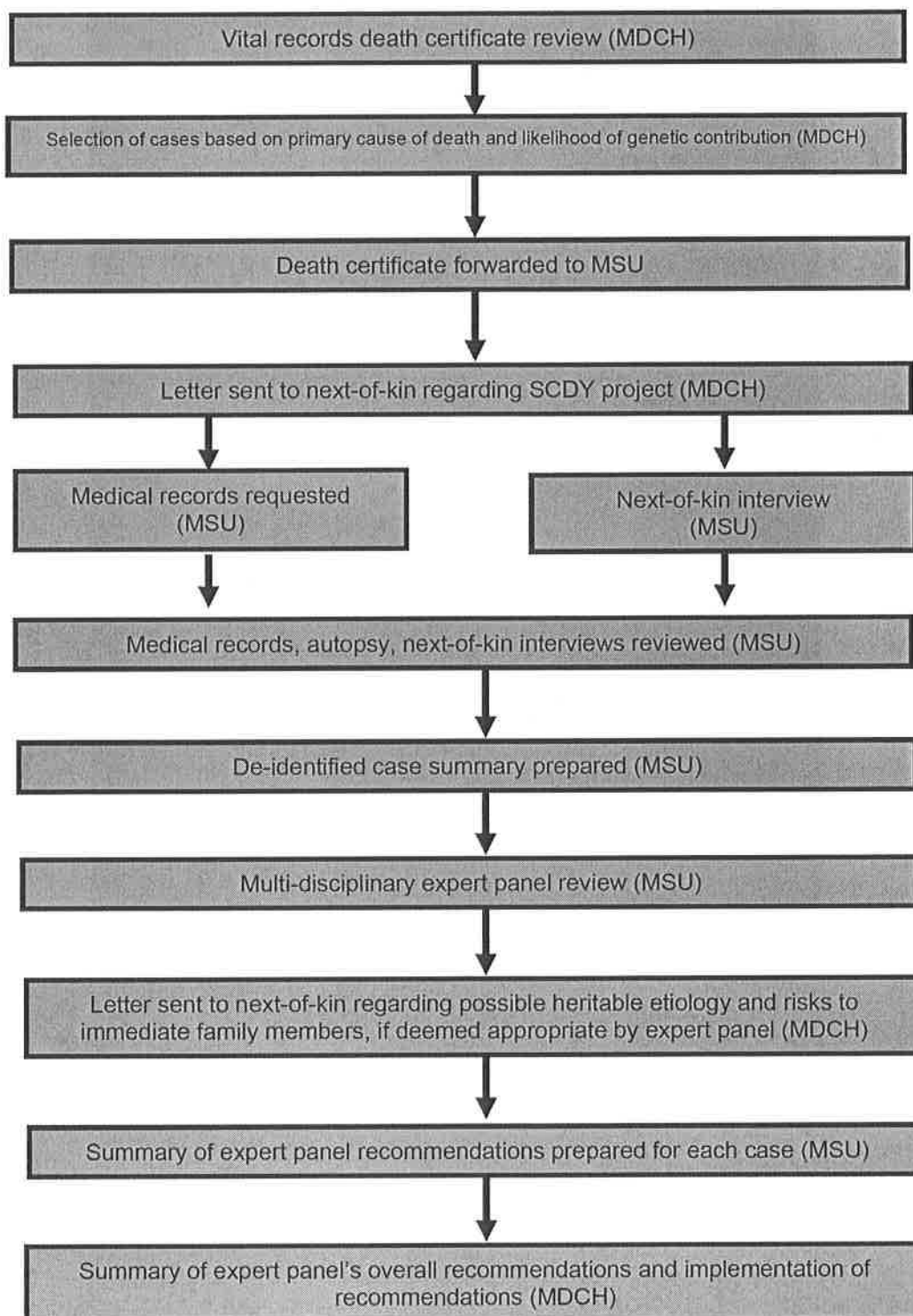
### Development of SCDY Data to Action in Michigan

#### Highlights of Key Steps

- ♥ **Interviews with key medical experts**—provided important information about current practice and procedures following unexpected deaths, revealing considerable variation and lack of consistency in medical examiner post-mortem protocols from county to county.
- ♥ **Presentation to the state cardiovascular health advisory committee**—confirmed interest in developing a mortality review system.
- ♥ **Symposium on SCDY**—invited national and state experts to review causes of SCDY and set priorities; stakeholders (including family members and advocacy groups) identified the need for a state surveillance system and awareness campaign.
- ♥ **Analysis of existing mortality records**—reviewed death certificate data from 1999-2009 retrospectively to estimate burden of SCDY.
- ♥ **Population survey**—provided estimates of how many Michigan families are affected by SCDY based on answers to a question on the 2007 BRFS (a BRFS random-digit-dialed telephone survey) about family history of SCD in young relatives.
- ♥ **SCDY investigation protocol and data collection instruments**—reviewed by MDCH Institutional Review Board (IRB), and project deemed to be of public health surveillance.
- ♥ **MDCH Medical Research Designation**—issued by MDCH Chief Medical Executive as allowed by the Public Health Code to assure that all information collected during the project is kept confidential and used only for public health purposes.
- ♥ **Michigan SCDY Expert Review Panel**—met for the first time in October, 2007 to review four SCDY cases. The panel met twice in 2008 to review nineteen SCDY cases. Sixteen next-of-kin were interviewed. Twenty-one action items to primary and secondary prevention of SCDY were identified. Published in Journal of Community Health in 2010 (9).
- ♥ **Call to Action Event** – held on September 18, 2008 with 60 participants to discuss and identify key next steps to prevent SCDY in Michigan.
- ♥ **Listserv Formed**- listserv was created in September 2008 and includes individuals interested in next steps to prevent SCDY in Michigan.
- ♥ **Workgroups Formed**- three workgroups were formed in October 2008 to address the next steps to prevent SCDY in Michigan; one is the pre-participation sports screening workgroup which has over 55 members.
- ♥ **Consensus Based Recommendations for Pre-Participation Sports Screening adopted by MHSAA**- pre-participation sports screening workgroup reviewed published literature and existing forms in all 50 states. Workgroup and over 20 Michigan organizations approved form based on the 2010 consensus form from the American Academy of Pediatrics, American Academy of Family Physicians, et al and the 2007 12-point American Heart Association recommendation. The workgroup's form was approved by MHSAA in December 2010 and began dissemination in 2011.
- ♥ **MDCH SCDY Website & Other Resources Created**- website created at [www.michigan.gov/scdy](http://www.michigan.gov/scdy); video created to increase awareness of SCDY and steps to prevent; expert web-based presentations on a variety of SCDY topics created.

## Appendix B

### SCDY Expert Mortality Review Process and Roles of Michigan Department of Community Health (MDCH) & Michigan State University (MSU)



## Appendix C

### International Classification of Diseases and Related Health Problems (ICD-10) Codes Utilized for SCDY Case Definition

Code	Disease
I00-I09	Rheumatic heart disease
I11	Hypertensive heart disease
I20-I25	Myocardial infarction; Atherosclerotic disease
I30-I31	Pericardium disease
I33	Endocardium disease
I34-I38	Valve disorders
I40	Myocarditis
I42	Cardiomyopathy
I44-I45	Conduction disorders
I46	Cardiac arrest
I47-I49	Cardiac dysrhythmias
I50	Heart failure
I51	Complications and ill-defined heart disease
Q20-Q24	Congenital abnormalities of the heart
Q87.4	Marfan syndrome
R96-R99	Ill-defined causes of death



**Appendix D**  
**Age-Adjusted Mortality Rates by County of Residence**  
**Ten-year age-adjusted mortality rate per 100,000 persons aged 1-39**  
**years of age, 1999-2009**

County	Rate	95% Confidence Interval	Number of SCDs
Alcona	-	-	-
Alger	-	-	-
Allegan	3.6	(2.1-5.0)	22
Alpena	7.2	(2.7-11.7)	10
Antrim	3.9	(0.5-7.4)	5
Arenac	-	-	-
Baraga	-	-	-
Barry	2.5	(0.8-4.3)	8
Bay	6.1	(4.0-8.1)	34
Benzie	-	-	-
Berrien	6.4	(4.7-8.2)	53
Branch	5.4	(2.6-8.2)	14
Calhoun	5.1	(3.5-6.7)	38
Cass	3.5	(1.2-5.7)	9
Charlevoix	3.8	(0.5-7.1)	5
Cheboygan	4.3	(0.8-7.7)	6
Chippewa	3.5	(1.0-6.0)	8
Clare	7.1	(2.9-11.3)	11
Clinton	2.9	(1.2-4.7)	11
Crawford	-	-	-
Delta	4.4	(1.3-7.5)	8
Dickinson	4.8	(1.0-8.6)	6
Eaton	3.2	(1.7-4.7)	18
Emmet	5.0	(1.5-8.4)	8
Genesee	6.7	(5.7-7.7)	164
Gladwin	-	-	-
Gogebic	6.3	(0.8-11.7)	5
Grand Traverse	4.7	(2.7-6.6)	21
Gratiot	4.6	(1.8-7.3)	11
Hillsdale	6.2	(3.0-9.4)	15
Houghton	2.6	(0.1-5.1)	5
Huron	5.7	(2.0-9.4)	9
Ingham	4.6	(3.7-5.9)	78
Ionia	3.1	(1.3-4.8)	12
Iosco	-	-	-
Iron	-	-	-
Isabella	4.2	(1.9-6.5)	15
Jackson	5.5	(3.9-7.0)	50
Kalamazoo	3.9	(2.8-5.0)	53
Kalkaska	5.4	(0.7-10.1)	5
Kent	4.1	(3.4-4.8)	146
Keweenaw	-	-	-
Lake	-	-	-
Lapeer	1.5	(0.7-2.3)	14

County	Rate	95% Confidence Interval	Number of SCDs
Leelanau	-	-	-
Lenawee	1.7	(0.9-2.5)	17
Livingston	1.5	(0.9-2.1)	27
Luce	-	-	-
Mackinac	-	-	-
Macomb	2.3	(2.0-2.6)	203
Manistee	-	-	-
Marquette	1.0	(0.2-1.9)	6
Mason	5.0	(2.3-7.8)	13
Mecosta	2.5	(0.9-4.2)	10
Menominee	2.2	(0.3-4.2)	5
Midland	1.7	(0.8-2.6)	14
Missaukee	4.4	(0.9-7.9)	6
Monroe	2.9	(2.0-3.8)	44
Montcalm	5.4	(3.6-7.1)	35
Montmorency	-	-	-
Muskegon	4.0	(3.0-4.9)	68
Newaygo	2.9	(1.3-4.4)	13
Oakland	2.0	(1.7-2.2)	251
Oceana	3.0	(0.9-5.1)	8
Ogemaw	-	-	-
Ontonagon	-	-	-
Osceola	3.4	(0.9-6.0)	7
Oscoda	-	-	-
Otsego	4.6	(1.9-7.3)	11
Ottawa	1.2	(0.8-1.6)	32
Presque Isle	-	-	-
Roscommon	5.4	(2.0-8.8)	10
Saginaw	3.2	(2.4-4.0)	62
St. Clair	2.4	(1.7-3.2)	42
St. Joseph	2.3	(1.1-3.5)	14
Sanilac	4.1	(2.2-6.1)	17
Schoolcraft	-	-	-
Shiawassee	3.1	(1.8-4.4)	22
Tuscola	2.5	(1.1-3.8)	13
Van Buren	1.8	(0.8-2.8)	13
Washtenaw	1.6	(1.2-2.0)	63
Wayne	5.6	(5.2-5.9)	1166
Wexford	2.3	(0.5-4.1)	7

Source: MDCH Vital Statistics

- Insufficient data, less than five deaths in the county

## Appendix E

### Common Causes of Sudden Cardiac Death

\*single or multiple genes play a role in determining susceptibility to most of these conditions

Anatomical Abnormalities	
<b>Aortic root aneurysm/ dissection</b>	Some aortic root aneurysms can be caused by genetic connective tissue diseases that weaken the aortic wall causing aortic aneurysm and subsequent death due to aortic dissection. Examples include Marfan syndrome, familial thoracic aortic aneurysms and dissections, and vascular type Ehlers-Danlos syndrome.
<b>Aortic stenosis</b>	An abnormal narrowing of the aortic valve that impairs blood flow to the arteries and can lead to heart failure, this is three times more common in men than women.
<b>Dilated cardiomyopathy (DCM)</b>	Left ventricular enlargement and systolic dysfunction, which usually results in heart failure with symptoms of congestion and/or reduced cardiac output, arrhythmias, and thromboembolic disease, including stroke. Genetic and acquired (non-genetic/idiopathic) forms exist.
<b>Hypertrophic cardiomyopathy (HCM)</b>	Unexplained left ventricular wall thickening in the presence of a non-dilated left ventricular cavity. HCM can often be genetic. It occurs in 1 in 500 individuals, and is reportedly the most common cause of SCDY in U.S. athletes.
<b>Mitral valve prolapse</b>	A "floppy" heart valve that can lead to irregular or rapid heartbeats and shortness of breath. Some may be caused by Marfan syndrome or Ehlers-Danlos syndrome.
<b>Myocarditis/ endocarditis</b>	An inflammation of the heart muscle, usually caused by viral infection but may occur as a complication of other medical conditions or exposure to drugs.
Arrhythmias	
<b>Arrhythmogenic right ventricular cardiomyopathy (ARVC)</b>	The heart muscle becomes thin due to an abnormal amount of fat and scar tissue in its walls. Mainly affects the right side of the heart. Most common cause of SCDY in Italian athletes.
<b>Brugada syndrome</b>	An electrocardiographic pattern of right bundle branch block, ST segment elevation in leads V1 to V3, and sudden death. More common in young males and in Southeast Asians.
<b>Catecholaminergic polymorphic ventricular tachycardia (CPVT)</b>	Arrhythmogenic disorder characterized by exercise, stress- or emotional-induced ventricular tachycardia, syncope or sudden death in the absence of detectable structural heart disease.
<b>Long QT syndrome (LQTS)</b>	A disorder of the heart's electrical rhythm leading to an increase in the QT interval that is often asymptomatic. Symptoms may include fainting and an abnormal rate and/or rhythm of the heartbeat (arrhythmia). Deafness is also associated with one type of inherited LQTS.
<b>Short QT syndrome</b>	A disorder of the heart's electrical rhythm leading to a decrease in the QT interval. If untreated, irregular heartbeats can lead to symptoms including dizziness, fainting, cardiac arrest and sudden death.
<b>Wolff-Parkinson-White syndrome (WPW)</b>	A condition that results in an extra conduction pathway for electrical signals within the heart. Symptoms include dizziness, chest palpitations, fainting and rarely cardiac arrest.
Vascular Abnormalities	
<b>Coronary artery abnormality</b>	A malformation of an artery, present at birth but often undetected.
<b>Coronary artery disease (CAD)/Atherosclerosis</b>	Plaque build-up narrows the coronary arteries and reduces blood flow to the heart muscle. Blood clots are more likely to form, blocking blood flow. Over time, CAD can weaken the heart muscle, leading to heart failure or arrhythmias.

## Appendix F

### **Suggested history questions from the American Academy of Pediatrics et al., 2010**

1. Have you ever passed out or nearly passed out DURING or AFTER exercise?
2. Have you ever had discomfort, pain, tightness, or pressure in your chest during exercise?
3. Does your heart ever race or skip beats (irregular beats) during exercise?
4. Has a doctor ever told you that you have any heart problems (high blood pressure, high cholesterol, a heart murmur, a heart infection, Kawasaki disease, or other)?
5. Has a doctor ever ordered a test for your heart (for example, ECG/EKG or echocardiogram)?
6. Do you get lightheaded or feel more short of breath than expected during exercise?
7. Have you ever had an unexplained seizure?
8. Do you get more tired or short of breath more quickly than your friends during exercise?
9. Has any family member or relative died of heart problems or had any unexpected or unexplained sudden death before age 50 (including drowning, unexplained car accident, or SIDS)?
10. Does anyone in your family have hypertrophic cardiomyopathy, Marfan syndrome, arrhythmogenic right ventricular cardiomyopathy, long QT syndrome, short QT syndrome, Brugada syndrome, or catecholaminergic polymorphic ventricular tachycardia?
11. Does anyone in your family have a heart problem, pacemaker or implanted defibrillator?
12. Has anyone in your family had unexplained fainting, unexplained seizures, or near drowning?

## Appendix G

### References

**\*Repeated references have abbreviated format**

1. Michigan Health Statistics. Division for Vital Records and Health Statistics- Michigan Department of Community Health. February 2011.
2. American Heart Association. Heart and Stroke Statistics- 2011 Update. Dallas, Texas: American Heart Association; 2011
3. Michigan Department of Community Health. 2007 Behavioral Risk Factor Survey (BRFS).
4. Morales A, Cowan J, Dagua J et al. "The family history: an essential tool for cardiovascular genetic medicine". *Congestive Heart Failure*. 2008; 14: 37-45.
5. Feero WG, Guttmacher AE. "Genomics of Cardiovascular Disease". *The New England Journal of Medicine*. 2011; 365:22
6. Caulder MS, Avery CL, Raup SF, Cohle SD, Peyser PA, Lehmann ML. "Sudden Coronary Death in the Young: Kent County, Michigan, 1990-2002". Presented at 46th Annual Conference on Cardiovascular Disease Epidemiology and Prevention. American Heart Association. 2006
7. Mukerji S, Hanna B, Duquette D, Bach J, Rosenman K. "Sudden Cardiac Death of the Young in Michigan: Development and Implementation of a Mortality Review System" *J Community Health*. 2010 Dec; 35(6):689-97.
8. Chugh SS, Jui J, Gunson K, Stecker EC, John BT, Thompson B, Ilias N, Vickers C, Dogra V, Dya M, Kron J, Zheng A, Mensah G, McNulty J. "Current Burden of Sudden Cardiac Death: Multiple Source Surveillance Versus Retrospective Death Certificate-Based Review in Large U.S. Community". *Journal of the American College of Cardiology*. 2004; 44(6): 1268-1275
9. Tan HL, Hofman N, van Langen IM, van der Wal AC, Wilde AAM. "Sudden Unexplained Death: Heritability and Diagnostic Yield of Cardiological and Genetic Examination in Surviving Relatives". *Circulation*. 2005; 112: 207-213
10. Caulder et al, 2006
11. Cowan J, Morales A, Dagua J, Hershberger RE. "Genetic Testing and Genetic Counseling in Cardiovascular Genetic Medicine: Overview and Preliminary Recommendations". *Congestive Heart Failure*. 2008; 14: 97-105
12. Maron BJ, Moller JH, Seidman CE, Vincent GM, Dietz HC, Moss AJ, Towbin JA, Sondheimer HM, Pyeritz RE, McGee G, Epstein AE. "Impact of Molecular Diagnosis on Contemporary Diagnostic Criteria for Genetically Transmitted Cardiovascular Diseases: Hypertrophic Cardiomyopathy, Long-QT Syndrome, and Marfan Syndrome: A Statement for Healthcare Professionals From the Councils on Clinical Cardiology, Cardiovascular Disease in the Young, and Basic Science, American Heart Association". *Circulation*. 1998; 98: 1460-1471
13. Feero et al, 2011
14. Chopra N and Knollman BC. Genetics of sudden cardiac death syndromes. *Current Opinions in Cardiology*. 26:196-203
15. Barsheshet A, Brenyo A, Moss AJ, Goldenberg I. "Genetics of sudden cardiac death." *Curr Cardiol Rep*. 2011; 13:364-376.
16. Barsheshet et al, 2011
17. Kaltman et al, 2011
18. Michigan Department of Community Health, 2009 [personal communication].
19. Maron et al. "Recommendations and considerations related to preparticipation screening for cardiovascular abnormalities in competitive athletes: 2007 Update: a scientific statement from the American Heart Association Council on Nutrition, Physical Activity, and Metabolism: Endorsed by the American College of Cardiology Foundation." *Circulation*, 2007;115:1643-1655
20. Campbell R, Berger S. *Pediatrics*. August 2006, 118(2): 802-804
21. Montagnana M, Lippi G, Franchini M, Banfi G, Guidi GC. "Sudden cardiac death in young athletes." *Internal Medicine*. 2008; 47(15): 1373-8.
22. Maron et al, 2007
23. Maron BJ, Thompson PD, Puffer JC, McGrew CA, Strong WB, Douglas PS et al. "Cardiovascular preparticipation screening of competitive athletes. A statement for health professionals from the Sudden Death Committee (clinical cardiology) and Congenital Cardiac Defects Committee (cardiovascular disease in the young), American Heart Association". *Circulation*. 1996; 94: 850-856.
24. Sofi F, Capalbo A, Pucci N, Giuliattini J, Condino F, Alessandri F, Abbate R, Gensini GF, Califano S. "Cardiovascular evaluation, including resting and exercise electrocardiography, before participation in competitive sports: cross sectional study." *British Medical Journal*. 2008; 337:a346
25. Chaitman BR. "An Electrocardiogram Should Not Be Included in Routine Preparticipation Screening of Young Athletes". *Circulation*. 2007; 116: 2610-2615
26. Corrado D, Pelliccia A, Bjornstad HH, Vanhees L, Biffi A, Bjorjesson M, Panhuyzen-Goedkoop N, Deligiannis A, Solborg E, Dugmore D, Mellwig KP, Assanelli D, Delise P, van-Buuren F, Anastasakis A, Heidbuchel H, Hoffman E, Fagard E, Priori SG, Basso C, Arbustini E, Blomstrom-Lundqvist C, McKenna WJ, Thiene G. "Cardiovascular pre-participation screening of young competitive athletes for prevention of sudden death: proposal for a common European protocol: consensus statement of the Study Group of Sport Cardiology of the Working Group of Cardiac Rehabilitation and Exercise

- Physiology and the Working Group of Myocardial and Pericardial Diseases of the European Society of Cardiology." *European Heart Journal*. 2005; 26:516-524.
27. Myerburg RF, Vetter VL. "Electrocardiograms Should be Included in Preparticipation Screening of Athletes". *Circulation*. 2007; 116: 2616-2626
28. Paterick TE, Paterick TJ, Fletcher GF, Maron BJ. "Medical and legal issues in cardiovascular evaluation of competitive athletes". *JAMA*. 2005; 294: 3011-3018
29. Maron et al., 2007.
- 30 Halabchi F, Seif-Barghi T, Mazaheri R. "Sudden cardiac death in young athletes: a literature review and special considerations in Asia." *Asian Journal of Sports Medicine*. 2011,. 2(1): 1-15
- 31 Corrado et al, 2005
- 32 Steinvil A, Chundadze T, Zelster D, Rogowski O, Kalkin A, Galily Y, Perluk H, Viskin S. "Mandatory electrocardiographic screening of athletes to reduce their risk for sudden death proven fact or wishful thinking?" *Journal of American College of Cardiology*. 2011; 15;57(11):1291-6.
33. Myerburg and Vetter, 2007.
34. Chaitman et al, 2007.
35. Maron BJ, Bodison SA, Wesley YE, Tucker E, Green KJ. "Results of screening a large group of intercollegiate competitive athletes for cardiovascular disease". *Journal of American College of Cardiology*. 1987; 10:1214-1221
36. Fuller CM. "Cost effectiveness analysis of screening of high school athletes for risk of sudden cardiac death". *Medicine & Science in Sports & Exercise*. 1997; 29:1131-1138
- 37 Vetter VL, Dugan N, Guo R, Mercer-Rosa L, Gleason M, Cohen M, Vogel RL, Iyer R. "A pilot study of the feasibility of heart screening for sudden cardiac arrest in healthy children." *American Heart Journal*. 2011; 161:1000-1006.e3
38. Maron et al, 2007
- 39 Drezner JA. "Contemporary approaches to the identification of athletes at risk for sudden cardiac death." *Current Opinion in Cardiology*. 2008; 23(5):494-501.
- 40 Wheeler MT, Heidenreich PA, Froelicher VF, Hlatky MA, Ashley EA. "Cost effectiveness of preparticipation screening for prevention of sudden cardiac death in young athletes." *Annals of Internal Medicine*. 2010; 152(5):276-86.
- 41 Kaltman et al, 2011
42. Maron et al, 2007
43. Paterick et al, 2005
- 44 American Academy of Family Physicians, American Academy of Pediatrics et al. *Preparticipation Physical Evaluation*. Fourth Edition. 2010 . <http://ppesportsevaluation.org/>.
45. Maron BJ, Chaitman BR, Ackerman MJ, Bayes de Luna A, Corrado D, Crosson JE, Deal BJ, Driscoll DJ, Estes NAM III, Araujo CG, Liang DH, Mitten MJ, Myerburg RJ, Pelliccia A, Thompson PD, Towbin JA, Van Camp SP. "American Heart Association Scientific Statement: recommendations for physical activity and recreational sports participation for young patients with genetic cardiovascular diseases." *Circulation*. 2004, 109; 2807-2816
46. Thompson PD, Balady GJ, Chaitman BR, Clark LT, Levine BD, Myerburg RJ. "Task Force 6: Coronary Artery Disease". *Journal of the American College of Cardiology*. 2005; 45:1348-1353.
- 47 Maron et al., 2005.
48. <http://www.stopcardiacarrest.org>
49. American Heart Association. "Working Against Time." Downloaded on August 28, 2008 from [www.americanheart.org/cpr](http://www.americanheart.org/cpr)
50. Terry GC, Kyle JM, Ellis JM, Cantwell, J, Courson R, Medlin R. "Sudden Cardiac Arrest in Athletic Medicine". *Journal of Athletic Training*. 2001; 36(2):205-209
51. <http://www.americanheart.org/presenter.jhtml?identifier=3011764>
52. Terry et al, 2001
53. [http://www.americanheart.org/print\\_presenter.jhtml?identifier=3011859](http://www.americanheart.org/print_presenter.jhtml?identifier=3011859)
54. Courson R, Drezner J. "Inter-Association Task Force Recommendations on Emergency Preparedness and Management of Sudden Cardiac Arrest in High School and College Athletic Programs." *National Athletic Trainers' Association*. July 2006.
55. O'Riordan. "New Guidelines for Managing Sudden Cardiac Arrest During School Athletics CME/CE". *Medscape*. Valid for credit until April 14, 2009.
56. Courson and Drezner, 2006
57. Terry et al., 2001

- 58 Hazinski MF et al. "Response to cardiac arrest and selected life-threatening medical emergencies: the medical emergency response plan for schools. A statement for healthcare providers, policymakers, school administrators, and community leaders". *Pediatrics*. 2004; 113(1):155-168.
- 59 <http://www.kimberlysgift.org/>
- 60 <http://www.wesleonardheartteam.org/wes-leonard-heart-foundation/>
- 61 <http://kaylasteam.weebly.com/>
62. de Lorgeil M, Salen P, Defaye P, Mabo P, Paillard F. "Dietary Prevention of Sudden Cardiac Death". *European Heart Journal*. 2002; 23: 277-285
63. Virmani R, Burke A, Farb A. "Sudden Cardiac Death." *Cardiovascular Pathology*. 2001; 10: 275-282.
- 64 Kaltman JS, Thomson, PD, Lantos, J et al. Screening for sudden cardiac death in the young: report from a NHLBI Working Group. *Circulation* 2011; 123(17):1911-8.
- 65 Wren C. "Screening children with a family history of sudden cardiac death". *Heart*. 2006; 92:1001-1006
- 66 <http://www.sads.org/Medical-Professional-Education/SADS-Recommendations-for-Post-Mortem-Practices>
- 67 Basso C, Burke M, Fones P, Gallagher PJ, DeGouveia RH, Sheppard M, Thiene G, Van Der Wal A, Association for European Cardiovascular Pathology. *Pathologica*. 2010; 102(5):391-404
- 68 Vohra J, Skinner J, Semsarian C. "Cardiac genetic investigation of young sudden unexplained death and resuscitated out of hospital cardiac arrest." *Heart, Lung and Circulation*. 2011:1-5.
- 69 Allegue C, Gil R, Blanco-Verea A, Santori M, Rodriguez-Calvo M, Concheiro L, Carracedo A, Brion M. "Prevalence of HCM and long QT syndrome mutations in young sudden cardiac death-related cases." *Int J Legal Med*. 2011; 125:565-572.
- 70 Vincent GM. "Sudden cardiac arrest in the young due to inherited arrhythmias: the importance of family care.". *PACE* 2009; 32:S19-22.
- 71 Tan et al, 2007
- 72 Tester DJ, Ackerman MJ. Postmortem long QT syndrome genetic testing for sudden unexplained death in the young. *J Am Coll Cardiol* 2007; 49:240-6
- 73 Tan et al, 2007
- 74 Behr ER, Dalageorgou C, Christiansen M, Syrris P, Hughes S, Tome Esteban MT, Rowland E, Jeffrey S, McKenna WJ. "Sudden arrhythmic death syndrome: familial evaluation identifies inheritable heart disease in majority of families." *Eur Heart J*. 2008; 29(13):1670-1680
- 75 Tester DJ and Ackerman MJ. "The Molecular Autopsy: Should the evaluation continue after the funeral?" *Pediatr Cardiol* 2012.
- 76 Quillin JM, Bodurtha JN, Smith TJ. "Genetic screening and DNA banking at the end of life #206." *J Palliat Med*. 2011; 14(5):656-7.
- 77 Wren C. "Screening children with a family history of sudden cardiac death". *Heart*. 2006; 92:1001-1006.
- 78 Vohra et al, 2011
- 79 Chopra et al, 2011
- 80 Gladding PA, Evans CA, Crawford J, Chung SK, Vaughan A, Webster D, Neas K, Love DR, Rees MI, Shelling AN, Skinner JR. "Posthumous diagnosis of long QT syndrome from neonatal screening cards." *Heart Rhythm*. 2010; 7(4):487-8
- 81 Michigan Commission on Genetic Privacy and Progress Final Report and Recommendations, 1999. Available at: [www.michigan.gov/documents/GeneticsReport\\_11649\\_7.pdf](http://www.michigan.gov/documents/GeneticsReport_11649_7.pdf)
- 82 Michigan Public Health Code, M.C.L., 333.5431(7)(b)
- 83 [www.michigan.gov/biotrust](http://www.michigan.gov/biotrust)
- 84 <http://www.mhsaa.com/AbouttheMHSAA.aspx>
- 85 Michigan High School Athletic Association (MHSAA). "Cover Story: 4-H Heart-Head-Heat-History". *Benchmarks*. Fall 2011; 3(1):4-9.
86. <http://www.mhsaa.com/resources/physical.pdf>
- 87 American Academy of Family Physicians, 2010
- 88 MHSAA, 2011
- 89 <http://www.michigan.gov/mdch/0,4612,7-132-8347-235825--,00.html>
- 90 MHSAA, 2011
- 91 Michigan Public Health Code, 691.1504(4)
- 92 Kaltman JS, Thomson, PD, Lantos, J et al. Screening for sudden cardiac death in the young: report from a NHLBI Working Group. *Circulation* 2011; 123(17):1911-8.
- 93 <http://www.nhlbi.gov/meetings/workshops/scd-young.htm>
- 94 Kaltman et al., 2011

---

We are grateful for the support from the Centers for Disease Control and Prevention (CDC), Office of Public Health Genomics that has allowed the Division of Genomics, Perinatal Health and Chronic Disease Epidemiology staff to work with the MDCH Cardiovascular Health, Nutrition and Physical Activity Section, MDCH Division for Vital Records and Health Statistics, Michigan State University, Division of Occupational and Environmental and over 100 other partners to establish a surveillance system to monitor the occurrence of sudden unexpected deaths in the young and to implement actions to prevent these deaths. We are especially grateful to the residents of Michigan who have participated in the next-of-kin interviews and BRFS survey.

The Michigan Department of Community Health is committed to the vision that “Michigan will be a safe and healthy state where all people realize their fullest health potential and live enriched and productive lives”. Every life lost to SCD of the young distances us from achieving this vision. Together with our partners, MDCH will continue efforts to prevent SCDY in Michigan.

Development and implementation of the Michigan SCDY surveillance and expert case review system was supported in part by Cooperative Agreement #U58/CCU522826 from the Centers for Disease Control and Prevention from 2003 through 2008. Subsequent grant support from the CDC Office of Public Health Genomics allowed printing of this report as well as the previous version in 2009. Dr. Michael Lehman inspired this project by first identifying SCDY as an important public health genomics issue for Michigan and for that, we are appreciative. Clipart photos and graphics are from Microsoft Word.

MDCH is an equal opportunity employer, services and program provider.  
[www.michigan.gov/mdch](http://www.michigan.gov/mdch)

June 2012





# School Fires

## Findings:

- Fatalities from school fires are rare.
- The three leading causes for school structure fires are incendiary or suspicious (32%), cooking (29%), and heating (9%).
- The leading area of fire origin for school structure fires is the lavatory.
- Kindergarten through high school fires increase at the beginning and end of the academic year. School fires peak in July due to a spike in elementary school fires.

Using the past 3 years of data, for 2003 to 2005, from the National Fire Incident Reporting System (NFIRS) database, the yearly national fire loss for fires on nonadult school properties<sup>1</sup> is estimated at \$85 million. Such losses are the result of an estimated annual average of 14,700 fires that required a fire department response. Fires on school properties caused an average of approximately 100 injuries. No fatalities were reported to NFIRS during this period.<sup>2,3</sup> Forty percent of these school-related fires occurred outdoors on school property.<sup>4</sup> Trash fires accounted for 36% of these outside fires, and fires in open fields or woods accounted for an additional 19%. Forty-three percent of fires on school properties, an estimated 6,300 fires, were structure fires.<sup>5</sup> Slightly over half of these structure fires were confined to the object where the fire started, such as a small cooking fire (20%) or a fire confined to a trash can (28%). Six percent of fires on school properties were vehicle fires.

## Making Schools Safe

Given the improved safety of school structures today, the likelihood of a fire, such as the one that burned the school of Our Lady of Angels in 1958, where 92 children and 3 nuns died<sup>6</sup> after being trapped with no means of escape, is reduced greatly. Most schools built since the late 1970s are required to have sprinkler systems and use safer construction materials. However, due to high-profile events, such as the 1999 Columbine High School shootings, the needs of school security sometimes conflict with the requirements of fire safety. For example, exits may be restricted for security

reasons preventing escape should a fire occur.<sup>7</sup> As a result, fire safety experts have increasingly been asked to work in conjunction with security advisors to recommend security procedures that are consistent with the needs of fire safety. Such cooperation is necessary, especially since injuries per school fire are slightly higher than non-residential structure fires, as shown in Table 1.

**Table 1. Loss Measures for School Structure Fires (3-year average, 2003-2005)**

Loss Measure	All Non-residential Structure Fires	School Structure Fires
Loss per fire	\$25,349	\$14,948
Injuries per 1,000 fires	12.8	13.1
Deaths per 1,000 fires	0.9	0.0

Source: NFIRS 5.0 data only

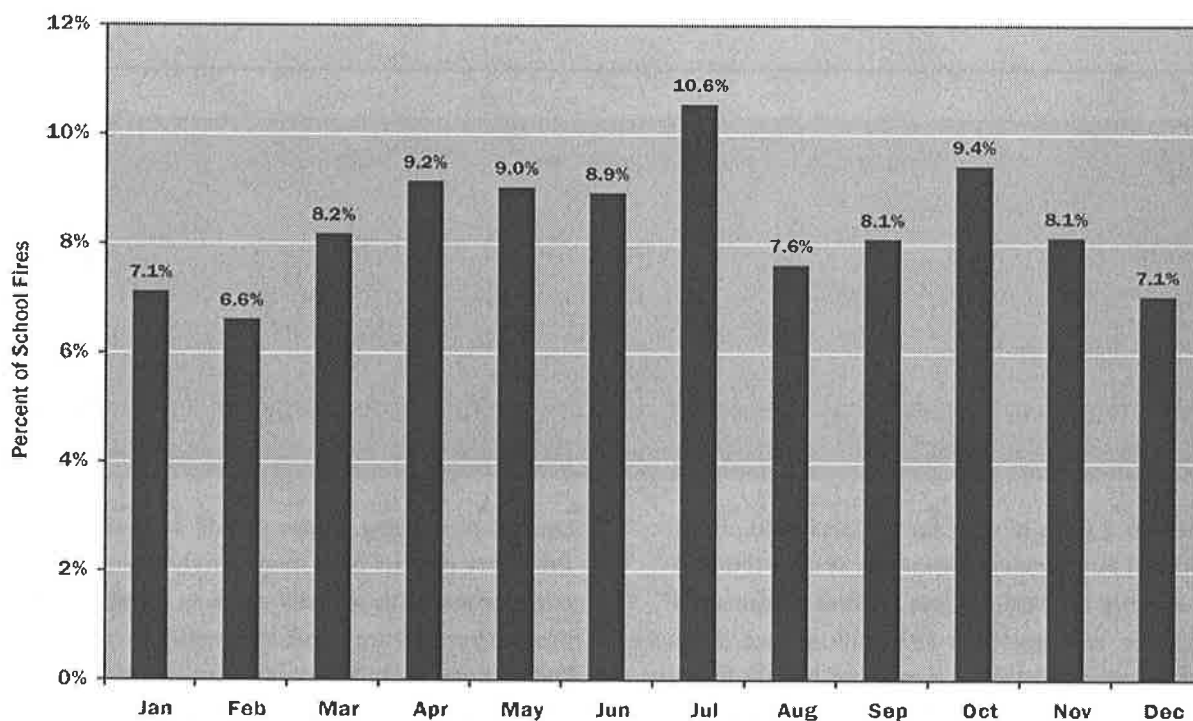
Note: Loss per fire is computed for only those fires where loss information was provided.

## When Fires Start on School Properties

Overall, the average peak month for fires on school properties was July; fire incidence was at its lowest between December and February, in the middle of the academic year (Figure 1). The July peak is driven by a sharp increase in fires at elementary schools as shown in Figure 2. It may be that elementary schools were more attractive targets for incendiary or suspicious fires during the summer when

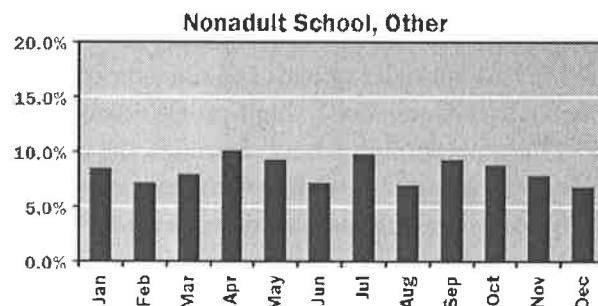
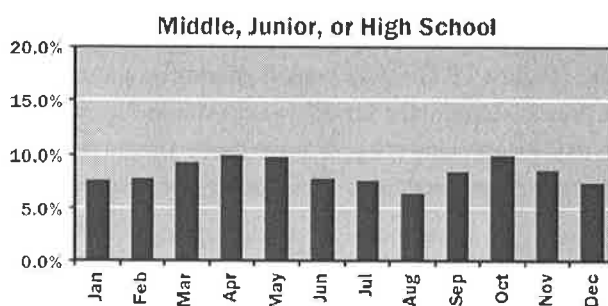
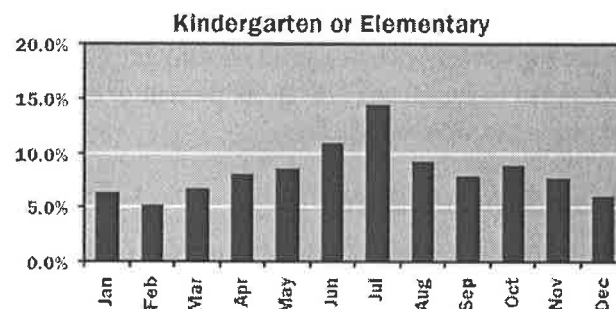
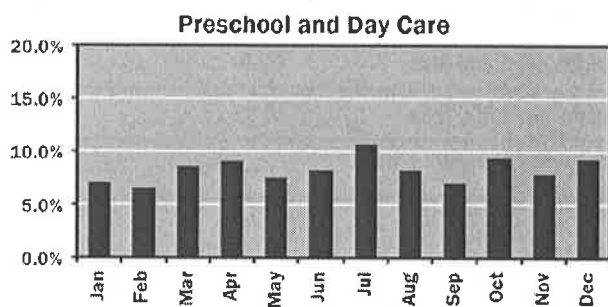
*continued on next page*

**Figure 1. Fires on School Properties by Month  
(percent, 3-year average, 2003-2005)**



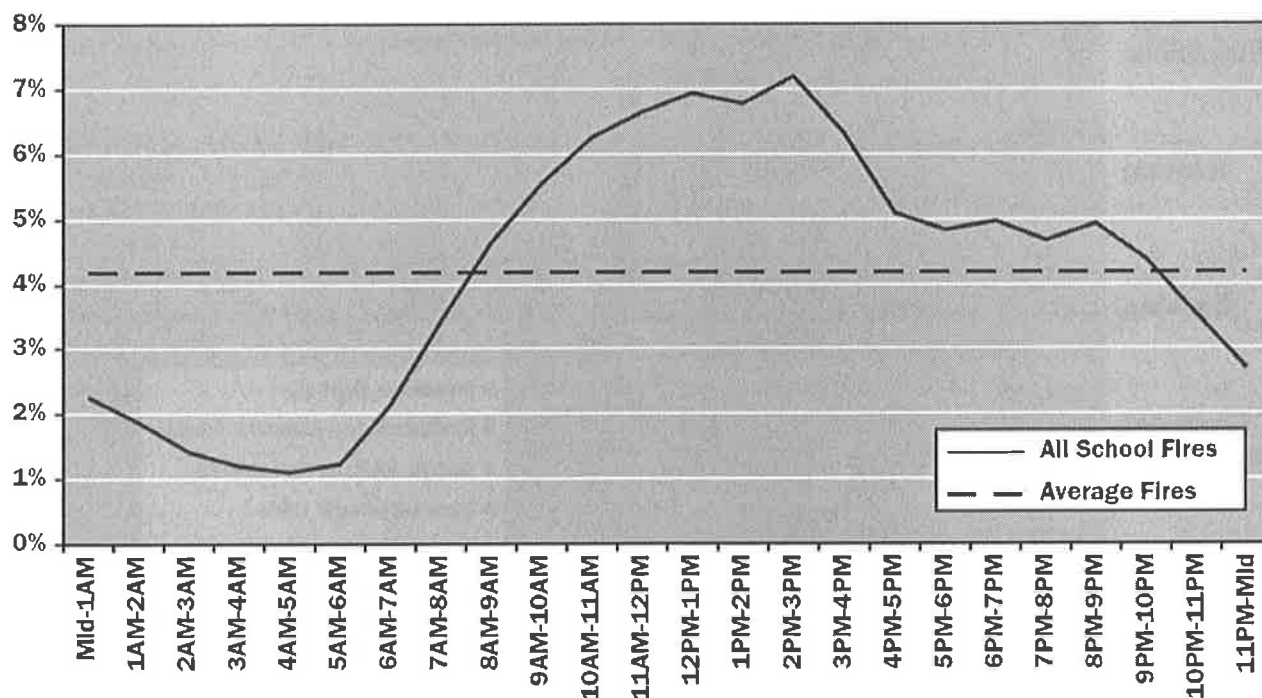
Source: NFIRS 5.0 data only

**Figure 2. Fires on School Properties by Month and Type  
(percent, 3-year average, 2003-2005)**



Source: NFIRS 5.0 data only

**Figure 3. Fires on School Properties by Time of Day**  
(percent, 3-year average, 2003-2005)



Source: NFIRS 5.0 data only

fewer school staff monitor the premises. Middle, junior, and high schools had above average fire incidence in the spring and fall—typically the end and beginning of the academic year (Figure 2). Fifty-five percent of fires on school properties occur between 8 a.m. and 5 p.m., the hours students are most likely to be in school, as shown in Figure 3. Thirty percent of fires occur between 5 p.m. and midnight; 15% occur between midnight and 8 a.m.

### Causes of School Structure Fires

Structure fires in preschool and day cares are predominantly due to cooking (64%) followed by heating (7%) and electrical distribution (6%), as shown in Figure 4. The causes for fires in kindergarten or elementary schools mostly involve cooking (27%), incendiary or suspicious activity (25%), and heating (12%). The primary cause of fires in middle, junior, or high school is due to incendiary or suspicious activity (47%), followed by cooking (15%), and heating (7%).<sup>8</sup>

Children may be the ones involved in setting arson fires in schools; unfortunately this cannot be determined from NFIRS data alone. As shown in Figure 5, the highest percentage of fires occurs in middle and high schools, followed by elementary schools. This distribution does not imply an associated age for a juvenile involved in the firesetting, but

does suggest the potential for middle- and high- school-age involvement.

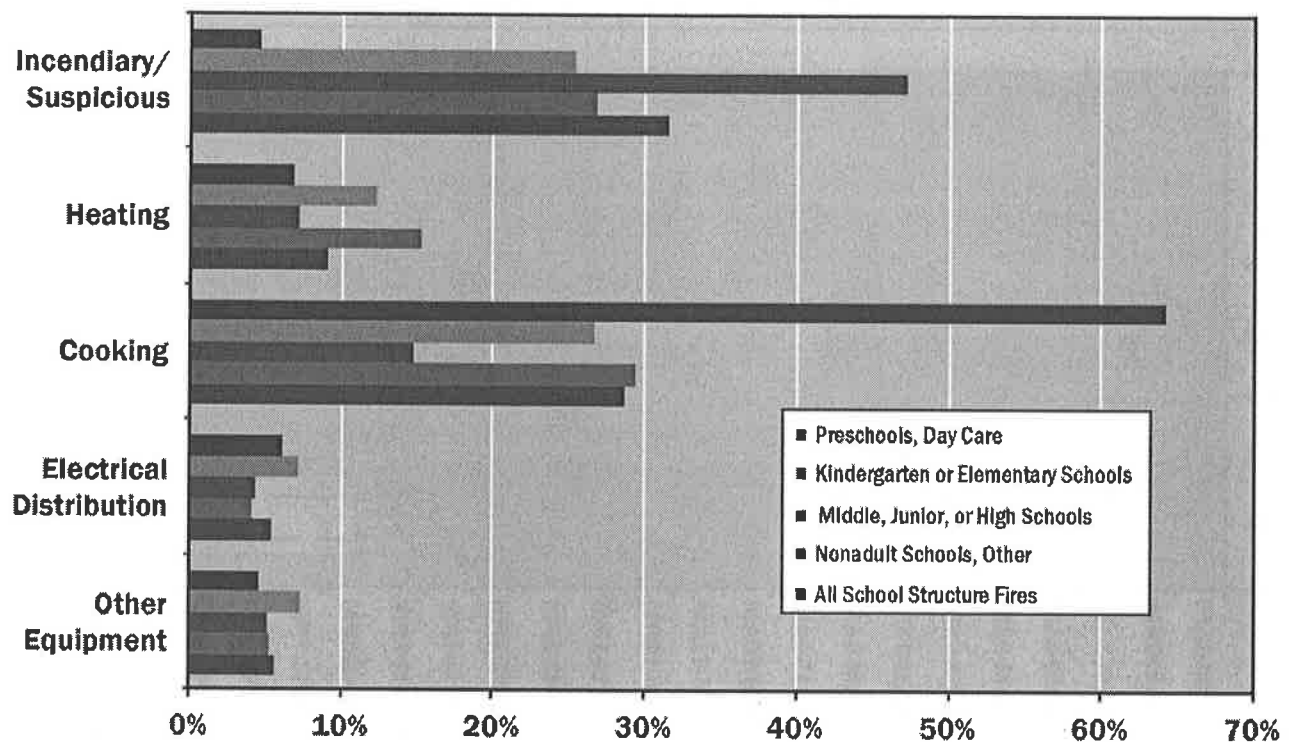
### Juvenile Firesetters

Forty-seven percent of all middle and high school structure fires and 25% of all elementary school structure fires are incendiary or suspicious in origin. Fifty-one percent of school structure fires occur in middle and high schools and 25% occur in elementary schools. This could explain the difference between intentional firesetting of older students and outdoor fireplay in younger students. In order to discourage fires initiated by young people, many studies and fire education programs target juveniles under the age of 18 years.

Juvenile firesetters, including elementary and high school students who exhibit fireplay or firesetting, generally fall into three basic classifications: 1) curiosity/experimentation, 2) reactionary, and 3) delinquent.<sup>9</sup> The first group involves younger children who experiment out of curiosity with common sources of ignition such as matches or lighters, and lack supervision. These children usually do not understand the danger associated with fireplay. Children who play with fire once are five times more likely to

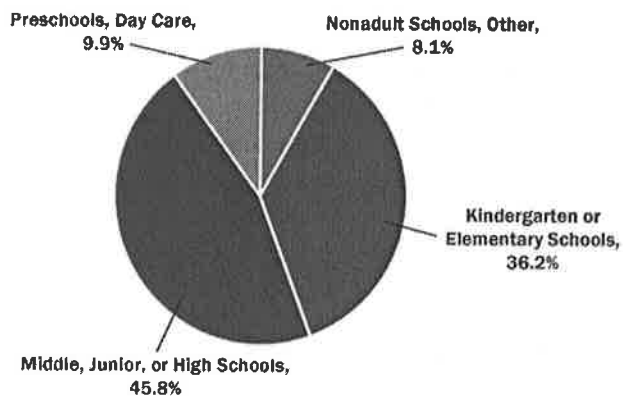
*continued on next page*

**Figure 4. Causes of School Structure Fires (percent, 3-year average, 2003-2005)**



Source: NFIRS 5.0 data only

**Figure 5. Fires on School Properties by School Type (percent, 3-year average, 2003-2005)**



Source: NFIRS 5.0 data only

experiment with fire again unless professional intervention takes place.<sup>10</sup>

Second, youth who do not have adequate problem-solving skills or cannot express their feelings send warning signals when they use fire in a reactionary way to convey their

feelings. This group also lacks supervision and has easy access to sources of ignition.

The third group, classified as delinquent and typically comprised of older children, set fires for an assortment of reasons that usually are peer-driven, such as pranks or dares, and showing off. Most members of this group do not realize the legal repercussions associated with setting fires.

However, adolescents who do understand the legal repercussions, yet continue to set fires, represent a growing problem. These fires qualify as intentional, with little respect for life or property. Youth in this group are more likely to associate with gangs and other gang-like activity, and may possess a potential for future violent behavior.<sup>11</sup>

A partnership among teachers, fire service, and the judicial system allows early identification of firesetters. In particular, teachers should report all fires immediately to the local fire service. Quick and full reporting helps the community recognize children using fire in inappropriate and unsafe ways. By providing fire education and, if necessary, psychological intervention, the chances for reducing juvenile-set fires increase substantially.<sup>12</sup>

continued on next page

## Where School Structure Fires Start

The three leading areas of fire origin in school structure fires are the bathroom, kitchen, and small assembly areas. One quarter of school structure fires start in bathrooms. These fires typically start in bathroom trash cans and are primarily of an incendiary or suspicious origin. Older students smoking in bathrooms also may increase the risk of such fires — over three quarters of fires in school bathrooms (78%) occur in high school, junior high school, or middle school bathrooms. Bathrooms present children and young teens with a place to set a fire without having to contend with constant adult supervision. Kitchens (7%) are the second leading area of origin for structure fires, reflecting cooking fires. Most of these kitchen fires, 43 percent, occur in preschool and day care kitchens. Small assembly areas for less than 100 people are the third most frequent place for school structure fires and typically occur in high schools, junior high schools, or middle schools.

**Table 2. Leading Areas of Fire Origin of School Structure Fires by Type of School (percent of fires, 3 year average, 2003-2005)**

Type of School	Area of Fire Origin		
	Bathroom	Kitchen	Assembly area < 100 persons
Overall	25	7	6
Preschool and Day Care	4	43	9
Kindergarten and Elementary	13	27	29
High School/Junior High School/Middle School	78	24	53
Other Nonadult School	6	7	8

Source: NFIRS 5.0 data only

## Material Ignited in School Structure Fires

The most common materials ignited in school structure fires are paper (25%), plastic (14%), wood<sup>13</sup> (11%), and fabric (9%). These materials, reflecting the high incidence of both incendiary and trash fires, are consistent with materials frequently used by juvenile firesetters and are accessible materials found in and around schools.

## Examples

Each year, newspapers are filled with stories regarding school fires. Below are four examples of such fires:

- On April 23, 2007, a 16-year-old Needville High School student in Fort Bend County, Texas confessed to setting the fire that destroyed two Needville High School buildings.<sup>14</sup>
- On March 26, 2007, a possible arson fire tore through the courtyard of Peralta Elementary School in Oakland, California, damaging parts of the office, library, and adjacent classrooms, causing an estimated \$500,000 in damage.<sup>15</sup>
- On May 22, 2007, two teenagers were charged with trying to burn down Wake Forest-Rolesville High School in Wake Forest, North Carolina, so they wouldn't have to go to school. The teens tried to burn toilet paper rolls and a garbage can in a bathroom.<sup>16</sup>
- On June 26, 2007, a fire destroyed the playground at Edgemere Elementary School in El Paso, Texas. Witnesses reported seeing three teenagers flee the scene. Damage was estimated at \$100,000.<sup>17</sup>

## Conclusion

School security must not compromise fire safety. Both school safety and security needs should be addressed through cooperation between school security and the local fire service.

Early identification of young firesetters through teacher, fire service, and judicial system partnerships gives communities the opportunity to provide fire education and, if necessary, psychological intervention, which will reduce future juvenile-set fires.

Like most fires, those in schools are largely preventable through increased fire safety education, supervision, intervention, and technological innovation. For further information, particularly on juvenile firesetter intervention programs, contact your local fire department or the U.S. Fire Administration.

To request additional information or comment on this report, visit <http://www.usfa.dhs.gov/applications/feedback/>

## Notes:

<sup>1</sup> For purposes of this report, "fires on nonadult school properties" include all fires occurring on property used for nonadult education, from day care through high school.

<sup>2</sup> NFIRS 5.0 contains both converted NFIRS 4.1 data and native NFIRS 5.0 data. This topical report includes only native 5.0 data and excludes incident type '110' since it is a 4.1 conversion code.

<sup>3</sup> National estimates are based on 2003-2005 native version 5.0 data from the National Fire Incident Reporting System (NFIRS) and national fire loss estimates from the National Fire Protection Association's (NFPA) Annual Survey of fire loss. Fires are rounded to the nearest 100, deaths to the nearest 5, injuries to the nearest 25, and loss to nearest \$M.

<sup>4</sup> Distribution statistics and per-fire losses are based on 2003-2005 NFIRS 5.0 data.

<sup>5</sup> Ninety-six percent of school structure fires are fires in the building itself (versus other built structures such as fences). As a result, the analyses are easily applied to school building fires.

<sup>6</sup> Our Lady of the Angels School Fire, <http://www.olafire.com/>

<sup>7</sup> National Association of State Fire Marshals. "Catastrophic Fire Prevention Task Force, School Fires," [http://www.firemarshals.org/mission/catastrophic/docs/school\\_fire\\_project.pdf](http://www.firemarshals.org/mission/catastrophic/docs/school_fire_project.pdf), October 2001.

<sup>8</sup> The cause percentages reflect the revised cause methodology implemented by the USFA as of May 2007. The revised methodology takes advantage of data elements available in NFIRS 5.0. Comparisons to cause distributions prior to May 2007 may not be appropriate.

<sup>9</sup> Jamie Fry, SOS Fires: Youth Intervention Programs. "Youth firesetting: Collaboration Between Teachers and Fire Service Personnel for Early Identification and Intervention," <http://www.sosfires.com/Collaboration%20Between%20Teachers%20and%20Fire%20Service.htm>

<sup>10</sup> Office of the Washington State Fire Marshal, "Reporting School Fires," <http://www.wsp.wa.gov/fire/rptschfr.pdf>

<sup>11</sup> Jamie Fry, SOS Fires: Youth Intervention Programs. "Youth Firesetting: Collaboration Between Teachers and Fire Service Personnel for Early Identification and Intervention," <http://www.sosfires.com/Collaboration%20Between%20Teachers%20and%20Fire%20Service.htm>

<sup>12</sup> Office of the Washington State Fire Marshal. "Reporting School Fires, A Step-by-Step Guide for Teachers and School Administrators," <http://www.wsp.wa.gov/fire/rptschfr.pdf>

<sup>13</sup> Using the NFIRS 5.0 definition of type of material first ignited. Wood is defined as wood or paper, processed, other (60) and wood chips, sawdust, and shavings (61).

<sup>14</sup> Fort Bend Now. "Needville Teen Confesses to Setting Fire That Destroyed Two High School Buildings," <http://www.fortbendnow.com/news/2880/>, May 07, 2007

<sup>15</sup> Oakland Tribune. "Possible Arson Fire Damages Peralta Elementary," [http://findarticles.com/p/articles/mi\\_qn4176/is\\_20070327/ai\\_n18760474](http://findarticles.com/p/articles/mi_qn4176/is_20070327/ai_n18760474), March 27, 2007

<sup>16</sup> The News & Observer. "Teenagers Arrested in School Fires," [http://www.newsobserver.com/news/crime\\_safety/story/582519.html](http://www.newsobserver.com/news/crime_safety/story/582519.html), May 28, 2007

<sup>17</sup> Newschannel 9, KTSM-TV. "School Fires The Work of Arsonists," <http://www.ktsm.com/news/local/8198072.html>

## Related Topics:

- School Fires: Volume 4, Issue 6, December 2004, <http://www.usfa.dhs.gov/downloads/pdf/tfrs/v4i6.pdf>
- School Fires: Volume 2, Issue 9, March 2002, <http://www.usfa.dhs.gov/downloads/pdf/tfrs/v2i9-508.pdf>